ISSUES OF ELDERLY CAREGIVING: AN EXPLORATORY STUDY OF THE CAREGIVERS

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BY

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ABSTRACT

This is an exploratory study of caregivers who provide home care to elderly relatives aged 75 years or more, who require 24 hour supervision and whose only alternate care option is institutionalization.

The study addresses those factors that make home care possible for the caregiver; the usefulness of formal services presently in place; the impact on the lifestyle of the caregiver; and the relationship between enjoyment/satisfaction and the demands of the caregiving role.

A questionnaire was devised and administered by the researcher to each of the 29 respondents in a personal interview.

The caregivers reported that family support, their own commitment and formal services were crucial factors in their continuing ability to provide home care.

The respondents in this study are in receipt of an average of four hours of formal services weekly, primarily in the area of personal care. Over 90% rated these services as essential.

The results of this study have shown that the majority of the caregivers do not enjoy their role but derive satisfaction in care provision. Their lack of enjoyment is attributed to the experiencing of a high level of frustration, aggravation and anxiety almost daily. In addition, the caregivers are unable to take a vacation, socialize outside the home, entertain at home, sleep soundly at night and have very little privacy. Satisfaction appears to be related to their own personal sense of responsibility and commitment to the care recipient.

The results of this study also indicate a descrepency with regard to the issue of family support. Family visits, while relatively frequent, were not seen to be useful by the respondents. The issue of family dynamics and its impact on the caregiving role is a subject that needs to be addressed by future research.

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And last, but certainly not least, many thanks to Carolyne Angers, my typist and friend, who had the remarkable ability to make the last stages of this thesis an enjoyable experience.

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CHAPTER 1

REVIEW OF LITERATURE

I. INTRODUCTION

Several factors make family caregiving of the aged an important issue today. These factors include sharp increases in the population of those living to be very old (75 or older), the vulnerability of this group to debilitating illness necessitating continuous care, and a greater emphasis on home care services for the elderly, rather than institutionalization. This last factor has tended to place the burden of elderly care upon the family.

Concurrent with this development is a decrease in the number of potential family caregivers. This decrease is due to changing lifestyles and higher rates of employment among women who have been the traditional caregivers. As in all situations of increased demand and reduced supply, a state of tension is inevitable. To date, little attention has been given to these tensions and difficulties, and to the particular needs and quality of life of family members who care for the elderly.

The purpose of this study is to gain a better understanding of the impact of the care provider role upon a small number of persons who care for elderly relatives in the home. Specifically of interest is the identification of factors associated with satisfaction/dissatisfaction in the

performance of the family caregiver/provider role. Such information is relevant to the development of policies and programs that are sensitive to the special needs of caregivers of the elderly, and that will improve the overall quality of life for them and for seniors living at home.

A. Demographic Description of the Aged Population

In 1986, there were 2,725,000 Canadians aged 65 years or over (approximately 11% of the population). In Newfoundland and Labrador, the elderly population was 50,400 (almost 10% of the total population) (Statistics Canada, 1986). During the next 20 years, while the projected total population of Newfoundland and Labrador is expected to increase by 9%, the senior citizen population is expected to increase by 53.3% reaching a total of 77,300 (approximately 12% of the total population) (Statistics Canada, 1986).

By the year 2031, it is expected that one person in four will be 65 years of age or older. The number of people in the category of the "very old" (75 years or older) is expected to double in number (The Royal Commission on Hospital and Nursing Home Center Report, 1984).

These population projections are important for the future planning of services to the elderly and for determining the most effective means of implementing quality services. Studies have clearly indicated that persons over the age of 65 years are heavier users of expensive health care facilities than are individuals in other age categories

(The Royal Commission on Hospital and Nursing Home Center Report, 1984). The projected increase in the number of elderly who will require community and long term institutional care and the corresponding increase in costs entailed in providing these services is prohibitive.

The operating costs per bed for nursing homes in Newfoundland and Labrador have increased from a yearly average of $5,190 in 1973-74, to $20,000 in 1981-82. This increase is significantly greater than the inflation rate for the same 8 year period, and somewhat greater than the percentage increase in total operating costs per bed for hospitals in Newfoundland and Labrador. Nursing homes experienced a total percentage increase in costs of 287% as compared with the 265% increase that hospitals incurred between 1974 and 1982. This amounted to $56,000,000 for the year 1985-86, with an average growth rate of 10% (The Royal Commission of Hospital and Nursing Home Costs Report, 1984). At present, the annual cost per person over 65 years of age for community-based services is $25.30 for the province as a whole and $33.79 for the city of St. John's. Provincially, only 1.5% of the elderly population (with 3% in St. John's) receive services from community based programs (The Royal Commission of Hospital and Nursing Home Costs Report, 1984).

B. Institutional Care vs. Home Care

Gerontology research has documented the negative effects of institutionalization for the elderly and has

pointed to the importance of finding alternatives. Studies of institutionalized patients diagnosed as suffering from senile dementia report especially high rates of mortality among such patients compared to those remaining in the community (Blenkner, 1967). Furthermore, because of their difficulty in retaining new information, patients suffering from senile dementia may show greater impairment in unfamiliar settings, while in their own homes familiar cues can trigger well established habits (Plutsky, 1974).

The Royal Commission specifically recommends an increase in the funding of community based services, including home care, day care programs and respite services. Community based services are seen to be the most cost-effective approaches to services for seniors. Concern with quality of care is another important aspect in the planning of services. How community based services will impact upon elderly populations and their family caregivers merits examination.

II. ROLE OF FAMILIES AS CARE PROVIDERS IN THE LITERATURE

Historically, the family has assumed responsibility for the elderly by providing substantial physical, social and economic support. A major portion of home health services for the elderly and chronically ill are still provided by family members. Statistics in the United States show that 80% of all home health care for elderly individuals is provided by families (Brody, 1978) and 75% of

the aged live in the community (Carrillo, 1983).

Despite the changes in family structure brought on by a technological and industrial society, strong kinship ties still exist, and adult children still maintain relationships with their elderly parents (Shanas, 1979; Sussman, 1976). The degree of involvement varies depending on economic resources, family structure and the quality of relationships. However, families do not abandon the older person. They do provide substantial support.

The presence of the family with its necessary resources is a crucial factor in delaying, if not preventing, institutionalization of the chronically ill older person. Research findings confirm this fact as an important predictor of placement (Brody, 1978). A study of mental status and living arrangements of residents prior to nursing home admission suggests that for many individuals who are at high risk of being institutionalized, the absence of an effective family unit is a decisive factor (Maddox, 1975). A decision in favour of placement is not determined by the individual's functional capacities, but rather by the absence of a caring unit in the form of spouse or children (Brody et al, 1978). Soldo and Myers (1976) confirm that childless or low fertility women have a 15% higher chance of institutionalization before age 75 than do women who bore three or more children.

Likewise, Barney (1977) in her examination of

circumstances associated with nursing home utilization, found that individuals lacking strong family and economic supports are more likely to be prematurely admitted to nursing homes.

In addition, Wan & Weissart (1981) found that the availability of social supports is highly associated with increased levels of physical and mental functioning in the aged. Research findings point to a high correlation between an elderly person's status of having to live alone and his/her eventual institutionalization.

A. Who are the Caregivers?

Female members of the family of the elderly disabled, such as spouses and daughters, are the predominant caregivers (Reece, 1983; Robinson, 1979; Synder & Keefe, 1985). This fact is seen to have important implications for those concerned with supporting the family caregiver.

The mean age of spouses or caregivers of the elderly is 65 years old (Statistics Canada, 1986). Cantor (1983), points out that spouses fall into the highest risk group as caregivers because of their low household incomes and the likelihood that they are old and infirm themselves. Frequently the elderly couple are living alone without children at home to assist with caregiving.

The mean age of children caring for aged parents is 53 years (Statistics Canada, 1986). Ill health and the death of one parent, with the subsequent concern for the

emotional, physical and financial status of the surviving parent, are circumstances which increase the likelihood of assistance being provided by children. Such conditions frequently result in parent and child sharing a household together (Shanas, 1962; Stenover, 1968). Neuman (1975) reports that when disability of the parent reaches the point that extended care is needed, only two alternatives are considered: moving the parent to the home of a relative, most often that of a child, or to a nursing home.

Those persons who are already engaged in the process of confronting the fact of their own aging are seen to be the ones who face the responsibility of care for their parents. Robinson & Brody (1966), suggest that if adult children are having to confront their own problems of aging, this may precipitate the institutionalization of the parent. Professionals, usually physicians, to whom adult children turn for help in coping with an aging parent, tend to recommend institutionalization, rather than alternatives involving home support (Calkins, 1972).

B. Differences in the Gender Roles of the Caregiver

While children routinely provide care to aging parents in the form of companionship, financial aid, gifts, advice and counsel, these family exchanges reveal a gender difference in the division of labour in the care of an older parent. Lapata (1973) reports that Chicago-area widows found their sons helpful in managing funeral arrangements

and financial matters, while their daughters fostered close emotional ties by listening and giving emotional support. It is the daughters who take widowed mothers into their homes, run errands, and provide custodial care. Females are seen to feel a greater responsibility for helping parents than males (Gray & Smith, 1960; Townsend, 1968). Hewss & Markson (1989) also refer to middle-aged daughters acting as caregivers, with sons or sons-in-law taking on a mainly managerial role. Men, unlike women, appear not to have been socialized to feel responsible for the emotional well-being of others (Adams, 1972).

Robinson & Turner (1972) found that men appear to have greater ability to distance themselves physically and emotionally from their parents. They also appear to experience less guilt and are more able to accept the view that making their parents happier is not within their power. Men who did have a high degree of contact with dependent parents were more likely to have negative perceptions of parents than women. Men recognized economic responsibilities and instrumental tasks, but unlike women, seldom felt responsible for the emotional well-being of the parent. They were also more likely to counsel the wife not to become overly involved with her own mother. Male physicians were found to play a similar role in advising women to lessen their contact with an emotionally harrowing mother. In addition, studies indicate that it is female

caregivers who consistently report experiencing more stress than males. (Horowitz & Dobrof, 1982).

The gender differences in the division of labour extend to both the performance of caregiving tasks as well as the nature of requests for formal service. Snyder & Keefe (1985) found that housework assistance was more frequently requested by males while women sought the help of support groups. These differences may be due to sex role training in that men have not been trained to perform household chores while women view housework as their duty. This study revealed that few men requested support group or emotional counselling. Males were viewed as being socialized to be independent of others and emotionally restrained. The major responsibilities for psychological sustenance and physical maintenance of the aged parent is seen to be assumed by the female family member. Such acceptance of the responsibility is associated with reported higher levels of stress among women as compared to men.

C. Caregiver Stress

Studies of stress among caregivers examine the phenomenon from a number of different perspectives. However, the findings point to a similar conclusion. The institutionalization of an older family member appears to be associated with the collapse of family supports under the weight of the growing responsibilities. Kooperman-Bryden (1979) found that the primary family caregiver invested over

28 hours per week in physical and psychological assistance. She found that two out of three providers suffered some health loss, and nearly half experienced significant anxiety. Smith & Bengston (1979) documented the relief of stress and improvement in family relations following institutionalization of the older family member. The Snyder & Keefe (1985) study revealed that 70% of the caregivers report that their health was negatively affected by caregiving responsibilities to the elderly. Furthermore, it is shown that the longer persons have been caregiving, the more likely they will report health problems. Robinson (1979), in a 5 year study, found that coping with the perceived mental deterioration of a parent produced a stressful relationship and generally resulted in a negative portrayal of parents by children. Stress also resulted when the caregiving relationship was experienced as confining.

Other researchers have documented the capability of families to handle difficult caregiving tasks. In a study of three-generational homes, Culfound et al (1979) found that 60% of the respondents reported no adverse effects of this arrangement on family functioning, and that 90% were satisfied with the family's living arrangements. These findings occurred in spite of the fact that 40% of these families provided up to 40 hours per week of direct personal care. In the Sanford study (1975), involving situations where the older person has been institutionalized, 92% of

the family supporters felt they could accept the family member in the home if outside support were available.

Much has been written about the strain and lowered morale of caregiving daughters who concurrently look after a young family (Marcus & Jaeger, 1984). Their exhaustion is seen as the factor which often precipitates institutionalization of the elderly parent (Horowitz & Dobrof, 1982).

Stress on the caregiver is reported to be greatest when the cared for person shows mental dysfunction (Zarit et al, 1980). However, there is some disagreement among the researchers. Some found that mental deterioration led to the highest stress, while others noted that lack of family support produced the most suffering. While these results may appear contradictory, both factors would appear as sources of stress for individual caregivers.

Zarit et al (1980), in their study on the extent of the burden of care on caregivers of senile dementia patients, found that the instrumental activities of daily living required the most attention. However, the level of burden measured was less than expected, considering the complexity of the care. Contrary to expectations, none of the behaviour variables, including the frequency of memory and behaviour problems, the extent of cognitive impairment and the degree of functional impairment, were correlated with other levels of burden. Similarly, duration of the

illness was not related to burden. Only the frequency of family visits had a significant effect on the degree of the caregiver's feelings of burden. The burden was lessened in those situations where more visits were made to the impaired older person from other family members.

Snyder & Keefe (1985) found that of the 43% of caregivers who report receiving help from outside family members, only 28% indicate that family help is consistent and regular. These caregivers viewed such relief as insufficient. However, it could be assumed that regular and consistent assistance, other than "visits" would be considered helpful.

D. Impact of Relationship Characteristics

Findings suggest that the health status and activity level of the older person affects the general satisfaction of both generations (parents and children). Johnson & Bursk (1977) found that if an older person has good health and a positive attitude toward aging, a high quality relationship with the children exists. Shand (1962), found that as the dependencies of the older person increase, the result is a corresponding increase in family conflict situations.

Recent research literature draws attention to the relationship between the caregiver and the elderly. Interpersonal conflict between parent and child in the earlier years is reported to produce tension in the care of the elderly parent and the child (Kulys & Tobin, 1980),

whereas past experiences with older people and previous caregiving is said to lessen the strain (Sussman, 1979). A close affectionate relationship between a child caregiver and cared for parent is seen to lessen the strain in caregiving, whereas intimate bonds between caregiving spouses tend to heighten the level of perceived stress.

In studies on the abuse of the elderly by family members, it is reported that 40% of the elderly people aged 85 years and older are likely to be abused (Kosberg, 1983). Abuse is seen to occur for a variety of reasons which include the strain of caring, prolonged dependency, role reversal, unresolved conflict between parent and child, the elderly's lack of consideration for privacy, the inability to understand children as adults and the elderly's inability to relinquish power (Kosberg, 1983). Sengstock et al (1984) also report a combination of stress factors that can lead to abuse. Both studies suggest that psychological stress is greater than the demands of physical care.

These studies suggest that physical care in and of itself is not the primary reason for caregiver burnout; rather it is the combination of the high demands of physical care with the experience of great psychological stress which leads to burnout and/or elderly abuse.

III. CRITIQUE OF EXISTING RESEARCH

More recent studies provide some information on a variety of factors associated with family caregiving of the

elderly; there is agreement that assistance is required through the delivery of formal services to alleviate the burden of care. Respite care is seen as the most needed and sought after service, whether provided formally or informally (Reece, 1983; Snyder & Keefe, 1985; Sanford, 1975; Kosberg, 1983; Robinson, 1979).

Other studies have examined the various factors associated with family caregiving to the elderly, such as predictors of institutionalization of the aged, the nature of the relationship between caregiver and cared for person, and the emotional consequences for the caregiver as a spouse or as a child to the person receiving care. These studies provide information not previously documented by formal research. The focus of the research has been general in nature, however, giving information on the characteristics of the caregiver and elderly, the type of living situations and/or the types of medical problems or diagnoses encountered. These studies do not pinpoint specific factors that lead to caregiver burnout; neither do they show how to prevent institutionalization. The role of the elderly spouse as a mutual caregiver has not been given attention until recent years (Gislon, 1989), and little is known about elderly siblings as mutual caregivers.

IV. STATEMENT OF PURPOSE

Given the current research, it is clear that more specific questions on caregiver stress and burnout need to

be addressed. What are the factors that lead to caregiver burnout? What are the aspects of joint-living situations that professionals should be aware of in order to make appropriate needs assessments and service delivery decisions. Are patients with Alzheimer's Disease or Senile Dementia more difficult to care for at home than other "high-level" care patients who do not exhibit cognitive impairment? Are the elderly with problems of incontinence more likely to require early institutionalization?

This study focuses on a specific population not previously studied - the caregivers of a group of older persons aged 75 years and older who require 24 hour care, or the equivalent of institutional care. It has been predicted that the number of persons in this age group will double. Twenty four hour care is costly and time consuming. It requires a complex range of tasks that is taxing on the emotional well-being of the caregiver particularly if they are family members. The caregiver is central to the quality of life experienced by the elderly person. At the same time the consequences of care on the family caregiver are crucial and must be considered in the planning of appropriate community support services.

This study will explore and describe the type and frequency of problems encountered by family caregivers and the ways in which their lifestyle is affected by their role and by their attitudes towards this role. Information will

be sought regarding those problems which caregivers feel they are capable of coping with, and those characteristics or issues which they view as the main barriers to the continuing home care of the elderly. Specifically, this study will explore the following questions:

A. What are the most difficult problems encountered by caregivers in caring for the elderly requiring 24 hour care?

B. What are the factors that make continued home management possible?

C. How essential is the presence of formal services to the caregiver in maintaining the elderly at home?

D. What aspects of daily living are the most affected by the role of caregiver?

E. Is there a relationship between the levels of satisfaction perceived by the caregiver and the level of care demanded in the caregiving role?

F. Is there a relationship between the levels of enjoyment perceived in the caregiver role and the levels of care required by the recipient of care?

CHAPTER 2

METHODOLOGY

I. THE SETTING

A. History of St. John's Home Care Program

The St. John's Home Care Program, in St. John's Newfoundland, provided the setting for this study. As one part of its mandate, this program provides services to the elderly and their caregivers to enhance independence. Therefore, through this program, an easily accessible population group was available for research conditional upon obtaining consent from both the program directors and from potential respondents.

Because this study is essentially an exploratory one, an investigator-administered questionnaire was considered an appropriate tool for information gathering.

The St. John's Home Care Program was established in 1973, as a pilot project of the Canadian Federal Government under the auspices of the Department of National Health and Welfare. In 1974, funding responsibility was transferred to the provincial Department of Health. At that time, St. John's Home Care provided up to a maximum of 30 days of nursing and homemaking services to acute care patients upon their discharge from hospitals.

In 1982, a new service, the Home Support Program, was introduced as a direct response to needs identified in the

original Acute Care Program. The aim of this new program was to provide support services, primarily homemaking, to the elderly and their families. The Home Support Program was designed to enable the elderly to remain independent in their own homes and therefore to delay or avoid their admission to institutional care.

In 1985, a third program was added, the Continuing Care Program. This program was established to provide nursing, homemaking, social work, physiotherapy, and occupational therapy services to the chronically ill and disabled.

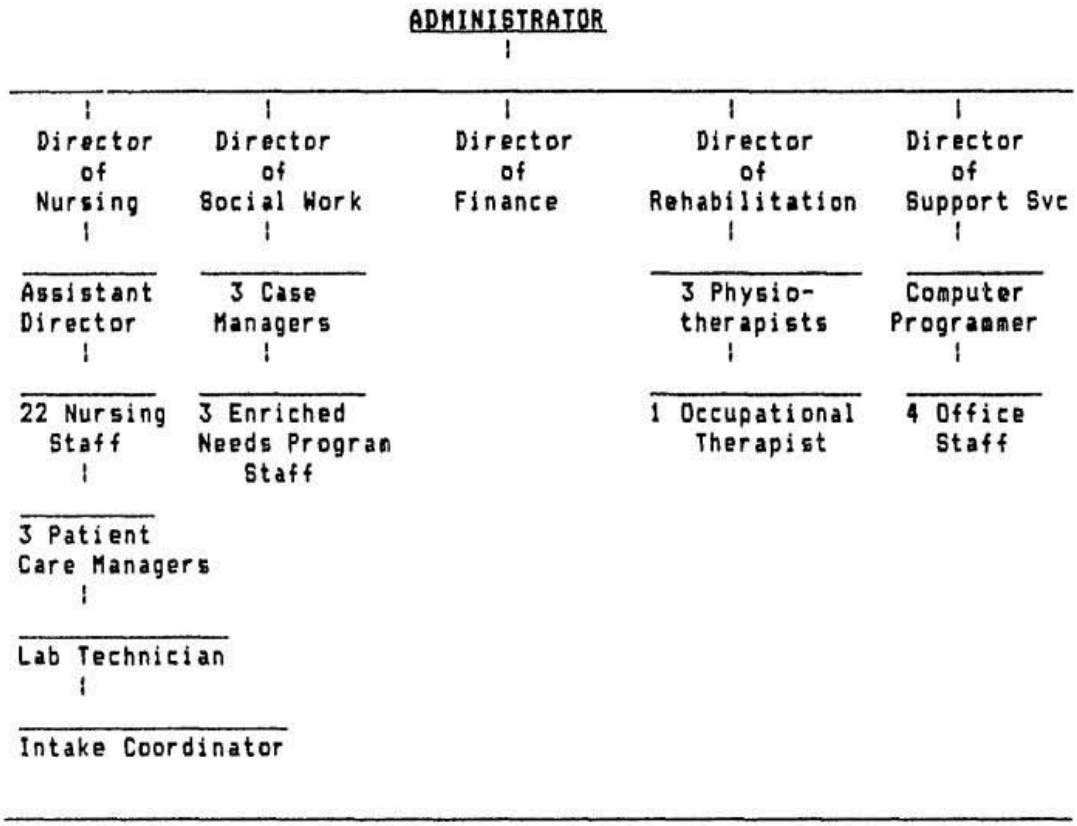
With the establishment of these three programs, a continuum of health care services became available to the elderly that promoted independent living at home. While, there are scattered, partial programs throughout the province, provided under the auspices of various hospitals, there is no overall provincial home care program. St. John's is the only location where a broad range of community based services consistent with need are available.

B. Organization & Internal Functioning of St. John's Home Care

The St. John's Home Care Program is a non-profit community agency accountable to a volunteer Board of Directors. Funding is provided by the Province of Newfoundland through the Department of Health. The Acute Care Program and Continuing Care Program are managed by professional nurses designated as Patient Care Managers, who

are directly responsible to the Director of Nursing. Caseloads are determined by city districts. In addition, social work and rehabilitation services are provided by the in-house staff. The Home Support Program is managed by professional social workers designated as Case Managers, who are responsible to the Director of Social Work. This program also has access to the other health professionals within the agency. Again, caseloads are assigned according to city districts. The Director of Rehabilitation has responsibility for physiotherapy and occupational therapy services provided in all three programs. In addition, there is a Director of Finance and a Director of Support Services responsible for the day to day functioning of the program. The agency is headed by the Administrator whose professional background is in social work. On the following page, Figure 1 represents the organizational chart of the agency.

FIBURE 1 ORGANIZATIONAL CHART OF ST. JOHN'S HOME CARE



All services are provided directly by the agency with the exception of homemaking which is purchased from a private group. There are no user fees charged for services. While referrals to the Acute Care Program can only be make by a physician, the Home Support and Care Programs can accept referrals from a variety of sources within the community such as a family member or other social agencies. Assessments for services are done in the home by Patient Care/Case Managers who also perform a liaison role with other community resources.

The St. John's Home Care Program promotes a philosophy aimed at furthering the continued independence of the patient while providing services based on need. Conjoint decision making between patient, family and agency is established at the first meeting. This approach is assumed to encourage self-sufficiency and responsibility for one's own health care. The agency's role is to provide the necessary supports, within its financial means, that enhance patient independence. This philosophy and approach differentiates St. John's Home Care markedly from institutional care such as is found in hospitals and nursing Homes.

II. THE SAMPLE

A. Selection Criteria

At the time of this study, the St. John's Home Care Program was serving a total population of approximately 500 people. Of these, 200 were on the Home Support Program, 200 were on the Continuing Care Program and 100 on the Acute Care Program.

The sample population was drawn from the Home Support and Continuing Care Programs using the following specific criteria:

1. Age of the care recipient -
   75 years or older.

2. Amount of supervision/care required 24 hours per day. (The Care recipient can no longer function alone. Care includes 24 hour supervision and/or total physical care).

3. Alternative Options for care - Institutionalization.

A sample population of 40 persons was randomly selected from a total population of 80 seniors and their family caregivers who met the above criteria.

The selection criteria ensure a degree of homogeneity within the group and eliminate that portion of the aged population who are still active and independent in their lifestyle while, at the same time, residing with a family unit.

Twenty nine respondents (36.25 %) of the total population of 80 agreed to participate in the study, which is a response rate of 72.5%.

B. Recruitment Procedures

Permission was obtained from the St. John's Home Care to contact potential subjects to elicit their agreement to participate in the study. An agency based Patient Care/Case Manager made the initial request by telephone, providing general information regarding the purpose of the research. Once consenting subjects became identified, the "General Information Letter" (Appendix I) was mailed by the investigator. This letter outlines in general terms, the

focus of the research, the means by which information would be collected and the appropriate assurances regarding confidentiality.

A follow-up phone call verified each potential respondents' decision to participate and a home visit was then arranged at the subject's convenience. The Informed Consent Form (Appendix II) was presented for the subject's signature at that time.

C. **The Instrument**

A structured questionnaire devised and administered by the researcher was used to collect the data utilized in this study (Appendix III). Each individual interview lasted between 60-90 minutes and all were conducted over a four week period.

The questionnaire is divided into six sections. Two focus primarily on a demographic description of the caregiver and care recipient and the remaining four sections address the six research questions specified in the Statement of Purpose:

1. Demographic profile of the caregiver
2. Demographic profile of the care recipient
3. Information on various kinds of physical care required by the care recipient
4. Identification of the impact on the caregiver's lifestyle

5. Examination of the emotional impact of caregiving for family members

6. Information on existing services being received and their use to the caregiver.

D. <u>Pre-testing of the Questionnaire</u> (Appendix III)

In June 1986, the questionnaire was used to collect data on five subjects randomly selected from the total population group of 80, as a pre-test.

The results of the pre-test provided information which led to the following changes in the questionnaire for interview purposes:

1. Section D which dealt with personal issues was switched with section E which dealt with available support services. The respondents appeared more comfortable answering questions about emotional experiences later in the interview, having had more time to relax with the interviewer.

2. In Section E, the following questions were deleted due to redundancy:

   a) How do you feel about your relationship as it exists today?

   b) Does it affect your feelings towards _____? They were replaced by "Have your feelings changed towards your _____?

3. In Section F, the following question was changed from "Are you able to manage the situation as it exists today?" to "What factors enable you to continue to care for your _____?

E. Variables Under Study

1. Characteristics of Care Providers

In Section A, a demographic profile of the caregiver is identified including age, gender, education, income and marital status. "Caregiver", in this study, is defined as the individual who has primary responsibility for the physical and emotional needs of the care recipient.

The nature of the kinship relationship between the caregiver and care recipient is included to determine its significance as a contributing factor to the degree of commitment experienced by the caregiver. In other words, does a daughter feel more committed to the care of a mother than a niece to an elderly aunt?

The number of children living at home and their respective ages is included among these demographic variables to ascertain if the additional task of child rearing infringes on the caregiver's coping ability.

Medical status of the care provider with its consequent impact on general feelings of well-being may be an additional factor that affects the caregiver's ability to function.

2. Characteristics of Care Recipient

In Section B, a similar demographic profile of the elderly relative is provided including age, sex and marital status.

Medical diagnosis, as a variable, is included to establish the type of special care related to medical problems that is required of the caregiver.

Questions 20 and 21, dealing with length of time of living together and number of years of providing full-time care are included as variables to determine if time is a significant factor directly related to caregiver satisfaction. Can it be assumed that the longer one provides such high level care the more stress will be experienced? Or does one adjust to the demands over a long period of time to the extent that it becomes part of a daily routine? Is such a long term involvement any more or less stressful than that experienced by the sudden unexpected burden of a 24 hour care relative? Such an occurrence can be totally disruptive to an existing family lifestyle. Does such a disruption have short term stress consequences which progressively decrease over time? Or does the stress increase, the longer one provides such a high level of care?

3. Behaviour of Care Recipient

In this section, the focus is on those behaviour patterns exhibited by the elderly relative and the resulting required physical care that must be provided by the caregiver.

The variables are subjected to two kinds of measurements: frequency of occurrence of problematic behaviour and level of difficulty this behaviour causes the caregiver.

Frequency of occurrence is measured along a three point scale: 1 = daily, 2 = weekly, 3 = monthly.

Level of difficulty is subjectively measured on a Likhart scale of one to five: 1 = no difficulty, 5 = great difficulty.

Sleep disturbances are identified as any behaviour that causes the caregiver to be awakened during the night in order to respond to the needs of the elderly person.

Dangerous or irresponsible behaviour designates any behaviour of the elderly that increases the risk to him/herself or any household member. This may include activities such as leaving a stove on or a burning cigarette unattended.

Frequent or unreasonable demands include repetitive requests that have already been attended or cannot be satisfied.

Inability to communicate includes physical impairments such as loss of speech or deafness or neurological problems resulting in confusion. Also included is the inability to respond on an emotional level or express appreciation.

Uncooperative behaviour is identified as continued, repeated reluctance to aid the caregiver in the provision of care.

4. Impact on Care Provider Lifestyle

This section examines the effects that the caregiver role has on the respondent's lifestyle. The respondents identified those aspects of day-to-day living that are affected by having to care for the elderly relative and they rated each on a Likhart Scale of one to five for major or minor effects. (1 = no effect, 5 = major effect).

Intrusion on privacy is defined as any restriction which may be imposed on private aspects of life such as conversations, relationships, personal time, as a result of the presence of the elderly relative.

Inability to leave elderly relative unsupervised refers to restrictions imposed on the caregiver in matters that prohibit the ability to freely leave the home to perform daily activities.

Interference with career can be defined as the inability to pursue one's career fully and without restraint, or the prevention of being employed due to the elderly relative's care.

Reluctance to being cared for by another person is identified as the relative's lack of willingness to accept care and/or supervision from any person other than the designated caregiver.

Restrictions in entertaining at home refers to any physical or emotional factor, associated with the elderly relative, which might prevent the respondent from inviting family or friends in the home socially.

Inability to take a vacation is categorized as those factors which might prevent the respondent from taking a vacation away from home for any period of time.

Inability to socialize outside the home is defined as those factors of caregiving that restrict the respondent's ability to leave the premises for the purpose of socializing. These factors may include lack of financial resources needed to hire a replacement, lack of family support, or worry about the elderly person during the caregiver's absence.

Inability to pursue a hobby is defined as any restriction on the caregiver's opportunity to develop and engage in personal interests. This restriction may include lack of time due to the demands of caregiving, or

interference by the care recipient that would make such activity unsatisfactory.

Intrusion on children's lives refers to any factors that inhibited the relationship between the respondent and his/her children whether or not they are living at home.

Financial hardship includes those aspects of caregiving, such as medical or physical needs, that may require the respondent's use of personal funds to the extent that is considered to be burdensome.

Inability to sleep soundly at night is defined as worry or stress related to caregiving that prevents the caregiver from sleeping soundly at night. This can include a concern for the future in terms of one's own personal health, the effects on family life, and the such.

The category of other is also included to account for other variables as provided by the respondent that may not have been taken into account in the questionnaire. None of the respondents could add to the list of variables.

5. Emotional Impact on Care Providers

This section addresses itself to the emotional responses of the respondent brought about by the relative.

Each respondent was asked to answer Yes or No to questions related to their experiencing enjoyment, satisfaction, frustration, anxiety, aggravation and resentment as a result of their care providing commitment.

In addition, the respondents were asked to rate the degree of the emotion experienced on a Likhart Scale of one to five. (1 = no experience, 5 = great experience).

Open-ended responses were sought on the specifics of the emotional experiences.

The emotional variables are defined as follows:

a) Enjoyment

This variable refers to the feeling of pleasure derived on a regular basis by the caregiver in that role. Were the activities of day-to-day care considered to be pleasant ones and of benefit to the caregiver?

b) Satisfaction

Does the caregiver derive a sense of doing "the right thing" and "feeling good" about taking on this responsibility. This variable also refers to a sense of "being needed" by a loved one and being able to respond to that need.

c) Frustration

This variable is included to determine if certain activities of caregiving are considered pointless in terms of achieving a goal, or causing a change for the better. The repetitiveness of daily tasks with no long term benefits is assumed to often be associated with a sense of frustration.

d) Anxiety

This variable is defined as a sense of worry or uneasiness brought about by the caregiving role, often associated with a sense of doubt of one's competence or worry about the future and continuing ability to provide care.

e) Aggravation

This variable is defined as a feeling of irritation towards the relative; a feeling that the situation would not improve despite one's efforts.

f) Resentment

This variable refers to a sense of unfairness and lack of appreciation of the respondent by the elderly relative. It may also express a wish to be relieved of the caregiver role and an increasing dissatisfaction with that role.

This section also examines the issue of family support. Research indicates that a supportive family aids in caregiving. Verification is sought with this population. For the purpose of this study, "other family members" refers to any relative not living in the same residence as the caregiver and the elderly relative.

The respondents are asked open ended questions which elicit information on whether or not their relationships with spouse, children and other family members are affected.

Similar questions are also asked regarding the availability of daily help and the occurrence of family visits. A Likhart Scale was used to rate the degree of helpfulness of family visits. (1 = not helpful, 5 = very helpful).

6. Adequacy of Community Services

The final section of the research questionnaire focuses on the types of services that are presently being received by the elderly relative and family caregiver.

While all the respondents are in receipt of services from St. John's Home Care, there are other services available to this population such as the V.O.N. or Meals on Wheels.

This section looks at how essential those services are in maintaining the caregiver's ability to continue providing the required high level of care.

In addition, respondents are asked to indicate what increase in services, if any, would be considered beneficial, and their willingness/ability to pay for such additional service.

CHAPTER 3

DATA ANALYSIS

I. DESCRIPTION OF THE PROCEDURES

This study examines the problems of family home care management of a group of elderly persons requiring 24 hour care. It seeks to identify those factors that enable family members to provide such high level care. In addition, this study seeks information on those problems that could lead to caregiver stress.

Essentially this is an exploratory study that addresses the following caregiver issues:

a) Primary source of difficulty;

b) Importance of existing formal services;

c) Lifestyle changes;

d) Factors that promote coping; and,

e) Relationship between feelings of satisfaction/enjoyment and the coping ability of the caregiver.

All continuous and nominal variables with two response groups were subjected to Pearson's correlational tests. F tests were completed for nominal variables having three or more response choices. This procedure was shown to facilitate making comparisons among statistical analyses. (Cohen & Cohen, 1975)

Preliminary manipulations were conducted as follows:

a) Variable 80 (Enjoyment) was established as a dependent variable and correlated with all others using Pearson's correlational tests.

b) Variable 82 (Satisfaction) was established as a dependent variable and correlated with all others using Pearson's correlational tests.

c) All "No" responses to variable 80 (Enjoyment) and all "Yes" responses to variable 82 (Satisfaction) were combined to form a new variable 115 (Satisfaction without enjoyment), which was then also subjected to frequency tests. The formation of variable 115 was an attempt to elicit information that might explain the seeming discrepancy between "No" to enjoyment and "Yes" to satisfaction in relation to caregiving.

The data analysis is presented as follows:

1. General Characteristics of Caregivers.
2. General Characteristics of Care Recipients.
3. Demands of the Caregiver Role
4. Perceived Effects on Emotional Well-Being of Caregivers.
5. Perceived Impact on Lifestyle.
6. Family Relationships and Support.

7. Utilization of Services.

8. Analysis of Variable 115 - Satisfaction without enjoyment and comparison of this group with the study's total population.

9. Pearson's co-relational tests on all variables vs. variable 80 (Enjoyment) and variable 82 (Satisfaction)

II. GENERAL CHARACTERISTICS OF THE CAREGIVER

TABLE 1 Caregiver Profile (N=29)

VARIABLE	MEAN	S.D.
AGE	59 yrs	13.21
INCOME	less than $10,000/year	
EDUCATION	Grade 11	
# of CHILDREN	3	1.71

Of the respondents, 82.7% are women (N=24) with 51.7% of this group being married (N=15). At the same time 48.3% are single, widowed, separated/divorced (N=14). 51.7% report having no significant health problems (N=15). The remaining 48.3% report either back problems, high blood pressure, arthritis or some heart related problems (N=14). However these medical problems are said to not significantly affect their role as caregiver. 34.5% of the respondents (N=10) have no children and the remainder have an average of 2 children. Those children who live at home (N=9) are all

over the age of 18. 44.8% of the respondents (N=13) have children living outside the province.

TABLE 2 Relationship of Caregiver to the Elderly (N=29)

RELATIONSHIP	NUMBER	PERCENTAGE
SPOUSE	7	24
PARENT	18	63
AUNT	1	3
SIBLING	1	3
OTHER	2	7

The majority of the caregivers (87.0%) are caring for a parent (N=18) or a spouse (N=7). The relationship between caregiver and care recipient in this study can therefore be considered very close in familial terms.

TABLE 3 Composition of Caregiver Household (N=29)

COMPOSITION	NUMBER	PERCENTAGE
ALONE WITH CARE RELATIVE	11	38
SPOUSE PRESENT	4	14
SPOUSE AND CHILD PRESENT	4	14
CHILD ONLY PRESENT	4	14
OTHER RELATIVE PRESENT	2	7
NON-RELATIVE PRESENT	1	3
PARENT(S) PRESENT	2	7
OTHER(S) PRESENT	1	3

Of the caregivers, 62.1% (N=18) live with at least one other person in the household besides the elderly relative. These other persons tend to be mostly a spouse and/or children. 38% of this group (N-11) live alone with the care recipient.

TABLE 4 Type of Residence (N=29)

RESIDENCE	NUMBER	PERCENTAGE
OWN HOME	14	48
RELATIVE'S HOME	6	21
RENTAL	9	31

Of the caregivers, 69% (N=20), live in a single family dwelling that is owned by either the caregiver (N=14) or the care recipient (N=6). The remaining 31% reside in rental accomodations.

III. GENERAL CHARACTERISTICS OF THE CARE RECIPIENT

TABLE 5 Care Recipient Profile (N=29)

VARIABLE	MEAN	S.D.
AGE	84	8.22
# OF LIVING CHILDREN	4	1.94
# OF YEARS W/CAREGIVER	31	20.95
# OF YEARS REQUIRING 24 HR CARE	5	3.85

The average age of the care recipient is 84 yrs old. 69% is female (N=20) and 72.4% have no spouse (N=21).

A significant factor regarding the care recipient is the length of time they have lived with the caregiver. 68.9% (N=20) have lived with the caregiver 30 years or longer. In addition, 24 hour care has been required for a period of 5 years or more for 51.7% of the group (N=15). For 41.4% (N=12) full time care has been necessary for 3 years.

TABLE 6 Health Problems of the Care Recipient (N=29)

HEALTH PROBLEMS	NUMBERS	PERCENTAGE
ALZHEIMER'S DISEASE	11	38
STROKE	5	17
SENILE DEMENTIA	4	14
HEART DISEASE	4	14
PARKINSON'S DISEASE	2	7
NONE	2	7
ARTHRITIS	1	3

Over half of this group (52%) have been diagnosed as having Alzheimer's Disease or Senile Dementia (N=15). The next highest category are those reporting heart problems/stroke (N=9). Primary care is directly related to the impact of the health problems experienced. Those who have reported no medical problems were unable to state a clear diagnosis. There had been no medical crisis at any time. The elderly person had become frail over time and

subsequently became bed ridden.

IV. DEMANDS OF THE CAREGIVER ROLE

Table 7 combines all of the information obtained in question 22 of the questionnaire (Appendix III). Specific problems or impairments characteristic of many elderly care recipients (obtained from St. John's Home Care assessment form) are listed in the order of their daily occurrence among this research population. The percentages of the table total in excess of 100% since some subjects of the study have reported more than one daily occurring problem which requires their attention or represents a demand of their time and physical or psychological resources.

Immediately to the right of the stated problem is the total number of respondents who reported its occurrence. In the middle column is the percentage of the total population of respondents for whom dealing with this specific problem is a daily requirement with the actual number of respondents in brackets. The percentages listed in the column located to the far right represent the number of caregivers who subjectively rate their dealing with this specific problem as being "very difficult" (4 or 5 on the 'level of difficulty' scale), even if their occurrence is relatively infrequent. Therefore, for the purpose of this study, only those problems that occur daily and that are experienced as very demanding by the caregivers are considered.

TABLE 7 Problematic Daily Behaviour of the Care Recipient (N=29)

BEHAVIOUR	DAILY OCCURRENCE	HIGH DIFFICULTY (ADJUSTED RATES)
INABILITY TO WASH UNAIDED (N=27)	89.7% (N=26)	51.8% (N=14)
INABILITY TO DRESS UNAIDED (N=21)	69.0% (N=20)	38.1% (N=8)
INABILITY TO COMMUNICATE (N=17)	55.2% (N=16)	58.8% (N=10)
SLEEPING DISTURBANCES (N=17)	51.7% (N=15)	64.7% (N=11)
INABILITY TO WALK UNAIDED (N=15)	48.3% (N=14)	40.0% (N=4)
INABILITY TO GET IN/OUT BED (N=14)	48.3% (N=14)	21.4% (N=4)
INCONTINENCE (N=13)	27.6% (N=8)	38.5% (N=5)
IMPAIRED VISION (N=12)	41.4% (N=12)	55.0% (N=6)
INABILITY TO GET ON/OFF COMMODE (N=12)	37.9% (N=11)	33.3% (N=4)
IMPAIRED HEARING (N=12)	37.9% (N=11)	55.0% (N=6)
DANGEROUS/IRRESPONSIBLE BEHAVIOUR (N=10)	27.6% (N=8)	66.6% (N=6)
UNCOOPERATIVE BEHAVIOUR (N=10)	24.1% (N=7)	57.0% (N=4)
FALLING (N=8)	3.3% (N=1)	87.5% (N=7)
INABILITY TO EAT UNAIDED (N=7)	24.1% (N=7)	28.6% (N=2)
UNREASONABLE/FREQUENT DEMANDS (N=7)	17.2% (N=5)	100.0% (N=7)
DAYTIME WANDERING (N=5)	13.8% (N=4)	80.0% (N=4)
PHYSICALLY AGGRESSIVE BEHAVIOUR (N=5)	6.9% (N=2)	40.0% (N=2)
INABILITY TO MANAGE STAIRS UNAIDED (N=3)	10.3% (N=3)	66.7% (N=2)

The most frequently reported daily activities are washing (N=27) and dressing (N=21). Washing was stated as

being very difficult by 51.8% (N=14) while only 38.1% (N=8) report dressing as difficult.

The inability to communicate and sleeping distrubances are also reported as occurring frequently and considered to be difficult. Seventeen respondents report daily occurrances of sleep disturbances and inability to communicate. Of these, 64.7% (N=11) report sleeping disturbances as very difficult with 58.8% (N=10) reporting high difficulty with communication problems.

The inability to walk (N=14) and get in and out of bed unaided (N=14) are also reported as daily occurrences by 48.3% of the group but this is not considered to be difficult (N=6; N=4).

While 44.8% (N=13) report incontinence, this occurs on a daily basis for only 27.6% (N=8) and is considered difficult for five of these people.

Dangerous and irresponsible behaviour occurs daily for 27.6% (N=8) of the total group and this is considered difficult for six of these eight respondents.

V. PERCEIVED EFFECTS ON EMOTIONAL WELL BEING OF THE CAREGIVER

In this section of the questionnaire, the investigator attempted to access data relating to six possible emotional reactions to the caregiving role.

As a first step, (Table 8) an overall "Yes" or "No" response was elicited, for example "Is caring for your elderly relative and enjoyable experience for you?". In a

second step the respondent was asked to rate the degree of enjoyment experienced on a scale of 0 to 5 with 0 representative of "No Enjoyment" and 5 of "High Enjoyment". The third step (Table 9) addressed itself to the frequency of occurrence of certain emotional reactions, rated as follows: 1=daily, 2=weekly, and 3=monthly. It should e noted that the investigator intended to include the variables of enjoyment, satisfaction and resentment in the third step (frequency). However, it became apparent that this question caused some irritation and anxiety for a major portion of the respondents. This whole section of the questionnaire was found to be difficult for the total group. The respondents attempted to address these issues honestly and clearly but were uncomfortable in delving in depth into their emotional responses and demonstrated this by becoming impatient. Therefore in order to continue to elicit their wholehearted cooperation with the questionnaire, it was believed to be expedient to delete frequency for these variables.

This same reaction was not apparent for the variables for frustration, anxiety and aggravation.

TABLE 8 Emotional Responses of the Caregiver (N=29)

EMOTIONAL ASPECTS	RESPONSE YES	NO	DEGREE EXPERIENCED 1	2	3	4	5	9
ENJOYMENT	11 37.9%	18 62.1%	4 13.8%	6 20.7%	11 37.9%	6 20.7%	2 6.9%	
SATISFACTION	27 93.1%	2 6.9%	3 10.3%	2 6.9%	4 13.8%	8 27.6%	12 41.4%	
FRUSTRATION	25 86.2%	4 13.8%	1 3.4%	4 13.8%	5 17.2%	7 24.1%	9 31.2%	3 10.3%
ANXIETY	19 65.5%	10 34.5%		2 6.9%	5 17.2%	5 17.2%	7 24.1%	10 34.6%
AGGRAVATION	24 82.8%	5 17.2%		2 6.9%	5 17.2%	10 34.6%	7 24.1%	5 17.2%
RESENTMENT	7 24.1%	22 75.9%	5 17.2%		2 6.9%	4 13.8%	1 3.4%	17 58.7%

TABLE 9 Emotional Aspects: Frequency of Occurrence (N=29)

ASPECTS	FREQUENCY 1	2	3	9
FRUSTRATION	14 48.3%	7 24.1%	4 13.8%	4 13.8%
ANXIETY	8 27.6%	5 17.2%	6 20.7%	10 34.5%
AGGRAVATION	7 24.1%	13 44.9%	4 13.8%	5 17.2%

Enjoyment: 11 (37.4%) subjects claimed to enjoy the role of caregiver, whereas 18 (61.1%) claimed to not find this role enjoyable. Only 10 subjects rated their enjoyment level at the lower end of the scale (1 or 2) compared to 18

who indicated no overall enjoyment, and only 8 rated their enjoyment in the upper ranges of the scale (4 or 5) compared to 11 who answered "Yes" to to the more general question. The mid-point of the "Degree of Enjoyment" scale was markedly the most favoured response category, nearly twice as popular as it's nearest options in either direction.

Satisfaction: 27 (93.1%) subjects stated that the role of caregiver gave them a sense of satisfaction. Of these, 20 rated the degree of satisfaction at the upper end of the scale (69%) and three only indicated such on the extreme lower end of the scale.

Frustration: 25 (86.2%) claimed that the caregiving role caused them to feel frustrated, with 16 (55.1%) feeling a high degree of frustration. Three respondents refused or were unable to rate their sense of frustration. Five chose the mid-point range and five stated a low level of frustration. 14 of the 25 (48.3%) stated that their sense of frustration occurred on a daily basis and seven reported this feeling weekly.

Anxiety: 19 (65.5%) reported feeling anxious about their role with 12 of these (41.3%) scoring high on the ratings scale. Five chose the mid-point range and only 2 reported a low level of anxiety. This group is almost divided equally in frequency of occurrence with 27.6% reporting anxiety daily, 17.2% weekly and 20.7% monthly.

Aggravation: 24 (82.8%) subjects stated that the caregiving role caused a sense of aggravation with 17 (58.6%) scoring on the upper range of the scale. Again, 5 respondents chose the mid-point range and only 2 reported on the lower end of the scale. Aggravation is experienced on a weekly basis by the largest proportion of the group (44.8%) with 24.1% reporting daily aggravation.

Resentment: 22 (75.9%) subjects report that they do not resent the caregiving role. Of the 7 who responded positively to the question, 5 report a high degree of resentment.

In summary, this group does not enjoy the caregiving role and found it to be frustrating, aggravating and the cause of some anxiety. At the same time, the respondents did not resent the caregiving role and found that it gave them a sense of satisfaction. Implications and further descriptions are discussed in more detail in Chapter 4.

VI. IMPACT ON CAREGIVER LIFESTYLE

This section of the questionnaire addressed the impact that the caregiving role has on the lifestyle of the respondents.

Each subject was asked to respond "Yes" or "No" to a list of conditions that directly applied to their individual situation. If a yes response was given the respondent was requested to indicate the degree of difficulty experienced by this condition on a Likert scale of 1 to 5. (1 = low

level, 5 = high level).

The percentages given in the far right hand column for level of difficulty are adjusted to those only responding "Yes". For example, 15 respondents reported that the care of their elderly relative was an intrusion on their privacy. Of those 15, 9 (60%) found this to be difficult. (Score 4 to 5)

TABLE 10 Impact on Lifestyle of the Caregiver (N=29)

CONDITIONS	RESPONSE		HIGH DIFFICULTY
	YES	NO	(ADJUSTED RATES)
INABILITY TO LEAVE UNSUPERVISED	27 93.1%	2 6.9%	23 85.2%
INABILITY TO SOCIALIZE OUTSIDE HOME	25 86.2%	4 13.8%	18 72.0%
INABILITY TO TAKE VACATION	23 79.3%	6 20.7%	22 96.5%
INABILITY TO SLEEP SOUNDLY	18 62.1%	11 37.9%	15 83.3%
INTRUSION ON PRIVACY	15 51.7%	14 48.3%	9 60.0%
RESTRICTION IN HOME ENTERTAINMENT	14 48.3%	15 51.7%	9 64.2%
INTERFERENCE WITH CAREER	10 34.5%	19 65.5%	6 60.0%
INABILITY TO PURSUE HOBBY	8 27.6%	21 72.4%	5 62.5%
RELUCTANCE TO BE CARED FOR BY ANOTHER	7 24.1%	22 75.9%	3 42.8%
PHYSICAL LIMITATIONS OF HOME	7 24.1	22 75.9%	3 42.8%
FINANCIAL HARDSHIP	6 20.7%	23 79.3%	2 33.3%
INTRUSION ON CHILDREN'S LIVES	4 13.8%	25 86.2%	3 75.0%
OTHER (REFUSED TO FOLLOW DIABETIC DIET)	1 3.4%	28 96.6%	1 100.0%

A large majority of the respondents report that the following categories were most impacted by the caregiving role:

a) Inability to leave unsupervised (93.1%);

b) Inability to socialize outside the home (86.2%);

c) Inability to take a vacation (79.3%);

d) Inability to sleep soundly (62.1%); and,

e) Intrusion on privacy (51.7%).

VII. FAMILY RELATIONSHIPS AND SUPPORT

This section addresses the role of family members in the life of the caregiver in terms of help received, visits and impact on relationships with family members.

Table 11 reports on family aid in caregiving tasks, visits and their usefulness, and frequency of visits. Table 12 reports on family relationships in terms of change.

TABLE 11 Family Support (N=29)

SUPPORT	YES	NO	NOT APPLICABLE
SPOUSAL AID	7 24.1%	2 6.9%	20 69.0
CHILDREN AID	10 35.4%	8 27.6%	11 37.9%
AID FROM OTHER FAMILY MEMBERS	8 27.6%	21 72.4%	0 0
FAMILY VISITS	21 72.4%	8 27.6%	0 0
HELPFULNESS OF FAMILY VISITS	11 37.9%	10 34.5%	8 27.6%

	DAILY	WEEKLY	MONTHLY	NONE
FREQUENCY OF FAMILY VISITS	8 27.6%	9 31.0%	4 13.8%	8 27.6%

While there are 15 subjects with spouses, only nine responded to the question on spousal aid. The reason for this seeming discrepency is that there are caregivers who are looking after their spouses and, therefore, do not have a spouse to assist them in the caregiving role.

Of those caregivers with spouses who are not care recipients 77.8% reported that they receive assistance in the caregiving role. Of those with children, 55.6% state that they receive aid from them. In addition, help from other family members is not forthcoming as only 27.6% (N=8) responded "Yes" to the question.

There is a high percentage of visits from other family members (72.4%, N=21) these visits which generally occur on a weekly basis are seen as helpful by 52.3% (adjusted percentage to those reporting) and are not considered useful by 47.7%.

TABLE 12 Change in Family Relatiohships (N=29)

RELATIONSHIP	IMPROVED	DETERIORATED	SAME	N/A
WITH SPOUSE	1 3.4%	2 6.9%	6 20.7%	20 69.0%
WITH CHILDREN	1 3.4%	4 13.8%	13 44.8%	11 38.0%
WITH OTHER FAMILY MEMBERS	1 3.4%	8 27.6%	17 58.6%	3 10.4%

The respondents generally indicate that family relationships had stayed the same over time while involved in the caregiving role. These results are further discussed in Chapter 4.

VIII UTILIZATION OF FORMAL SERVICES

The respondents reported on those services presently being used and rated their degree of usefulness on a Likert type 5 point scale (1=low, 5=high).

TABLE 13 Utilization of Formal Services: Frequency and Degree of Usefulness (N=29)

SERVICE	RESPONSE		DEGREE OF USEFULNESS (ADJUSTED PERCENTAGE)				
	YES	NO	1	2	3	4	5
PERSONAL CARE	25 86.2%	4 13.8%		1 4.0%			24 96.0%
SHORT TERM RESPITE	13 44.8%	16 55.2%		1 7.7%			12 92.3%
VISITING NURSE	9 31.0%	20 69.0%					9 100%
INSTITUTIONAL RESPITE	8 27.6%	21 72.4%					8 100%
HOUSEWORK	5 17.2%	24 82.8%					5 100%
DAYCARE	1 3.4%	28 96.6%					1 100%
PHYSIOTHERAPY	1 3.4%	28 96.6%					1 100%
MEALS ON WHEELS	0	29 100%					

Personal care is the most utilized service with 96% scoring 5 on the Likert scale for usefulness. 44.8% make use of a homemaker for short term respite with 92.3% of these scoring 5 on the Likert scale. Meals on wheels, daycare programs and physiotherapy are services that generally are not used by this group. Institutional respite is only used by 27.6% of the population. On the average, this group receives four hours of service per week and would find an additional two hours per week to be beneficial.

72.4% (N=21) would be willing to pay for additional hours of service. At present, the existing services have no fees charged to the users.

It is noteworthy that while these services are not extensive in terms of time, they are considered very useful and necessary. As previously reported, washing was stated to be a daily task that ranked high in difficulty. This task has been allieviated by formal service utilization.

It is also interesting to note that inability to take a vacation is regarded to be difficult by 79.3% of the group (N=22) and only 27.6% (N=8) take advantage of the institutional respite program. The implication of these results are discussed in Chapter 4.

IX. ANALYSIS OF VARIABLE 115: SATISFACTION WITHOUT ENJOYMENT COMPARISON OF RESULTS BETWEEN SUB-GROUP AND TOTAL POPULATION

Variable 115 was created by combining all the "No" responses to enjoyment to all the "Yes" responses to satisfaction. There were 17 respondents who claim to experience no enjoyment of their caregiving role, but who nevertheless seem to draw personal satisfaction from it. This new variable was then placed in the position of dependent variable vis à vis the other variables studied in this project.

TABLE 14 General Characteristics of the Caregiver (N=17)

VARIABLE	MEAN	S.D.
AGE	58	13.02
INCOME	less than $10,000/yr	
EDUCATION	high school or more	
NUMBER OF CHILDREN	1	.88

In some ways this group of 17 respondents seem to differ from the total group under study (not significantly from a statistical perspective). Mean age was lower by one year; their achieved level of education tended to be slightly higher (high school or more). 76.5% are female as opposed to 82.7% of the total population and they tend to have fewer children on the average (one instead of three).

TABLE 15 Relationship to the Elderly (N=17)

RELATIONSHIP TO THE ELDERLY	NUMBER	PERCENTAGE
SPOUSE	4	24.0%
PARENT	11	65.0%
AUNT	1	5.5%
OTHER	1	5.5%

The proportion of this group caring for a spouse or parent is similar to the ratios found in the total population (spouse: 24% and 24% respectively; parents: 65% and 63% respectively).

TABLE 16 Household Composition (N=17)

COMPOSITION	NUMBER	PERCENTAGE
ALONE WITH RELATIVE	7	40.0%
WITH SPOUSE	2	12.0%
SPOUSE/CHILDREN	2	12.0%
PARENT	2	12.0%
OTHER RELATIVES	2	12.0%
CHILDREN ONLY	1	6.0%
NON RELATIVES	1	6.0%

60% (N=10) live with another person in the household other than the care recipient. 40% live alone. This is similar to the total population.

TABLE 17 Type of Residence (N=17)

RESIDENCE	NUMBER	PERCENTAGE
OWN HOME	7	41.0%
RENTAL	6	35.0%
RELATIVE'S HOME	4	24.0%

The percentage of those living in their relative's homes and/or in rental housing is slightly higher than for the total group but the differences are very slight (24% vs 21%; 35% vs 31%).

TABLE 18 General Characteristics of Care Recipient (N=17)

VARIABLE	MEAN	S.D.
AGE	85	7.5
NUMBER OF LIVING CHILDREN	3	1.7
NUMBER OF YEARS WITH CAREGIVER	36	16.3
NUMBER OF YEARS REQUIRING 24 HOUR CARE	8	4

This sub-group does not appreciably differ from the total population of the study with regard to the mean age of the recipient and the average number of caregiver siblings. There are two notable differences between the two groups: the mean number of years spent with the caregiver and the mean number of years requiring 24 hour care. The total population lived with the caregiver for an average of 31 years and required 24 hour care for an average of 5 years or more.

TABLE 19 Care Recipient Health Problems (N=17)

DIAGNOSIS	NUMBER	PERCENTAGE
ALZHEIMERS' DISEASE	6	35.0%
STROKE	4	25.0%
SENILE DEMENTIA	3	18.0%
HEART DISEASE	2	12.0%
ARTHRITIS	1	5.0%
NONE	1	5.0%

A markedly higher percentage of care recipients in this sub-group have suffered strokes (25% vs 17%). Otherwise their health status is quite similar to that of the total study population.

TABLE 20 Behaviour Patterns of Care Recipients: Ranking by Frequency of Daily Occurrence for Sub-Group 115 (N=17) and Total Population (N=29)

PROBLEM	115 SUB-GROUP	TOTAL POPULATION
INABILITY TO WASH	88.2% (N=15)	89.7% (N=26)
INABILITY TO DRESS	70.6% (N=12)	69.0% (N=20)
INABILITY TO COMMUNICATE	64.7% (N=11)	55.2% (N=16)
SLEEPING DISTURBANCES	64.7% (N=11)	51.7% (N=15)
INABILITY TO WALK	47.1% (N=8)	48.3% (N=14)
IMPAIRED VISION	47.1% (N=8)	41.4% (N=12)
INABILITY TO GET IN/OUT OF BED	47.1% (N=8)	48.3% (N=14)
IMPAIRED HEARING	41.2% (N=7)	37.9% (N=11)
INABILITY TO GET ON/OFF COMMODE	35.3% (N=6)	48.3% (N=14)
UNCOOPERATIVE BEHAVIOUR	29.4% (N=5)	24.1% (N=7)
DANGEROUS/IRRESPONSIBLE BEHAVIOUR	23.5% (N=4)	27.6% (N=8)
INABILITY TO FEED SELF	23.5% (N=4)	24.1% (N=7)
UNREASONABLE/FREQUENT DEMANDS	23.5% (N=4)	17.2% (N=5)
INCONTINENCE	23.5% (N=4)	27.6% (N=8)
DAYTIME WANDERING	17.6% (N=3)	13.8% (N=4)
PHYSICALLY AGGRESSIVE BEHAVIOUR	11.8% (N=2)	6.9% (N=2)
INABILITY TO CLIMB STAIRS	11.8% (N=2)	10.3% (N=3)
FALLING	5.9% (N=1)	3.4% (N=1)

In Table 20, the caregivers in the Sub-group experience more problems than the total population with communication (64.7% vs 55.2%), sleeping disturbances (64.7%

vs 51.7%), uncooperative behaviour (29.4% vs 24.1%) and unreasonable/frequent demands (23.5% vs 17.2%).

TABLE 21 Behaviour Patterns of the Care Recipient: High Level (Score 4-5) of Difficulty for Caregiver

PROBLEM	SUB-GROUP 115	TOTAL POPULATION
INABILITY TO WASH	56.3% (N=9)	51.8% (N=14)
INABILITY TO DRESS	38.5% (N=5)	38.1% (N=8)
INABILITY TO COMMUNICATE	66.7% (N=8)	58.8% (N=10)
SLEEPING DISTURBANCES	72.7% (N=8)	64.7% (N=11)
INABILITY TO WALK	44.1% (N=4)	40.0% (N=6)
IMPAIRED VISION	25.0% (N=2)	25.0% (N=3)
INABILITY TO GET IN/OUT BED	37.5% (N=3)	21.4% (N=4)
IMPAIRED HEARING	57.2% (N=4)	55.0% (N=6)
INABILITY TO GET ON/OFF COMMODE	37.5% (N=3)	33.3% (N=4)
UNCOOPERATIVE BEHAVIOUR	42.9% (N=3)	50.0% (N=6)
DANGEROUS/IRRESPONSIBLE BEHAVIOUR	80.0% (N=4)	60.0% (N=6)
INABILITY TO FEED SELF	50.0% (N=2)	28.6% (N=2)
UNREASONABLE/FREQUENT DEMANDS	100% (N=6)	100% (N=7)
INCONTINENCE	50.0% (N=4)	38.5% (N=5)
DAYTIME WANDERING	66.6% (N=2)	80.0% (N=4)
PHYSICALLY AGGRESSIVE BEHAVIOUR	66.6% (N=2)	40.0% (N=2)
INABILITY TO CLIMB STAIRS	50.0% (N=1)	66.7% (N=2)
FALLING	75.0% (N=3)	87.5% (N=7)

The following behaviour patterns/problems cause difficulty for higher percentages of the sub-group than the total population:

a) Inability to wash (56.3% vs 51.8%)

b) Inability to communicate (66.7% vs 58.8%)

c) Sleeping disturbances (77.7% vs 64.7%)

d) Inability to get in/out bed (37.5% vs 21.4%)

e) Inability to feed self (50.0% vs 28.6%)

f) Incontinence (50.0% vs 38.5%)

However, as the actual number of people who experience difficulty in these areas is relatively low, the differences between the two groups are not significant.

TABLE 22 Effects on the Emotional Well-Being of the Caregiver (N=17)

EMOTIONAL ASPECTS	RESPONSE		LEVEL EXPERIENCED				
	YES	NO	1	2	3	4	5
ENJOYMENT		17 100%	4 23.5%	6 35.3%	6 35.3%	1 5.9%	
SATISFACTION	17 100%		2 11.8%	1 5.9%	3 17.6%	4 23.5%	7 41.2%
FRUSTRATION	15 88.2%	2 11.8%		2 13.3%	3 20.0%	3 20.0%	7 46.7%
ANXIETY	13 76.5%	4 23.8%		1 7.7%	5 38.5%	1 7.7%	6 46.2%
AGGRAVATION	14 82.4%	3 17.6%			2 14.3%	6 42.9%	6 42.9%
RESENTMENT	4 23.5%	13 76.5%			2 50.0%	1 25.0%	1 25.0%

There are very few statistical differences between the sub-group and the total population regarding the emotional aspects of caregiving. The only notable difference is that 76.5% of the sub-group said "Yes" to anxiety compared to 65.5% of the total population. There is also a significantly higher percentage within the sub-group who experience high levels of anxiety (53.9% vs 41.3%).

TABLE 23 Impact on Lifestyle of the Caregiver (N=17)

CONDITION	RESPONSE		HIGH DIFFICULTY
	YES	NO	(ADJUSTED RATES)
INTRUSION ON PRIVACY	11 64.7%	6 35.3%	7 63.6%
INABILITY TO LEAVE UNSUPERVISED	16 94.1%	1 5.9%	14 87.5%
INTERFERENCE WITH CAREER	6 35.3%	11 64.7%	4 66.7%
RELUCTANCE TO BE CARED FOR BY ANOTHER	4 23.5%	13 76.5%	2 50.0%
RESTRICTION IN HOME ENTERTAINMENT	9 52.9%	8 47.1%	8 88.8%
INABILITY TO TAKE A VACATION	14 82.3%	3 17.7%	13 92.8%
INABILITY TO SOCIALIZE OUTSIDE HOME	14 82.3%	3 17.7%	11 78.5%
INABILITY TO PURSUE HOBBY	4 23.5%	13 76.5%	3 75.0%
INTRUSION ON CHILDREN'S LIVES	2 11.8%	15 88.2%	2 100%
FINANCIAL HARDSHIP	5 29.4%	12 70.6%	2 40.0%
PHYSICAL LIMITATIONS OF HOME	5 29.4%	12 70.6%	2 40.0%
INABILITY TO SLEEP SOUNDLY	11 64.7%	6 35.3%	8 72.7%

In comparison to the total sample, the sub-group experienced somewhat greater difficulty in an increased number of areas of their lives that were impacted by the caregiving role. Those areas are compared as follows:

		Sub-Group (N=17)	Total Sample (N=29)
Inability to leave unsupervised	[Occurrence]	94.1%	93.1%
	[High Difficulty]	87.5%	85.2%
Inability to take a vacation		87.3%	79.3%
		92.8%	95.6%
Inability to socialize outside home		82.3%	86.2%
		78.5%	62.5%
Inability to sleep soundly		64.7%	62.1%
		72.7%	83.3%
Intrusion on privacy		64.7%	51.7%
		63.6%	60.0%
Restriction in home entertainment		52.9%	49.3%
		88.8%	64.2%

There are few statistical differences revealed in a comparison between the sub-group and the total group regarding the emotional impact of caregiving. There are, however, certain differences which, although not statistically significant, are certainly observable. The sub-group experiences more frequency of and greater difficulty with communication problems, sleeping disturbances and dangerous/irresponsible behaviour.

X. RESULTS OF CORRELATIONAL TESTS ON VARIABLES 80 AND 82

Pearson's correlational tests were performed on variables 80 (Enjoyment) and 82 (Satisfaction) with all other variables to determine if significant relationships existed. Only those significant at the .05 level are noted in this study.

TABLE 24 General Characteristics of Caregiver with Enjoyment and Satisfaction

VARIABLES	ENJOYMENT	SATISFACTION
AGE	.04	-.24
SEX	-.25	.17
KINSHIP	.16	.22
NUMBER OF CHILDREN	.37	-.27
HOUSEHOLD COMPOSITION	.03	.06
AGES OF CHILDREN LIVING AT HOME	-.43*	-.18
CHILDREN LIVING AWAY FROM HOME	-.05	-.19
MARITAL STATUS	-.06	.23
TYPE OF RESIDENCE	-.18	-.10
EMPLOYMENT STATUS	.21	-.09
INCOME	.19	.09
MEDICAL DIAGNOSIS	-.10	.22
EDUCATION	-.17	-.07

* Significant at the .05 level

An inverse relationship exists between enjoyment and the ages of children living at home.

TABLE 25 General Characteristics of Care Recipient with Enjoyment and Satisfaction

VARIABLES	ENJOYMENT	SATISFACTION
AGE	-.23	.12
SEX	.06	.11
MARITAL STATUS	.11	.38
NUMBER OF LIVING CHILDREN	.25	.04
NUMBER OF YEARS LIVING TOGETHER	-.18	-.30
NUMBER OF YEARS OF FULL TIME CARE	-.02	.18
MEDICAL DIAGNOSIS	-.11	-.06

A significant statistical relationship does not exist among and between these variables.

TABLE 26 Behaviour Patterns of Care Recipient with Enjoyment

BEHAVIOUR PATTERNS	FREQUENCY	LEVEL OF DIFFICULTY
SLEEPING DISTURBANCES	-.31*	.34
INCONTINENCE	-.07	.17
FALLING	-.13	.00
INABILITY TO GET IN/OUT OF BED	-.09	.33
INABILITY TO GET ON/OFF COMMODE	-.18	.13
DANGEROUS/IRRESPONSIBLE BEHAVIOUR	-.01	.17
INABILITY TO WALK UNAIDED	-.06	.27
UNREASONABLE/FREQUENT DEMANDS	-.43*	.00
PHYSICALLY AGGRESSIVE BEHAVIOUR	.12	.73
INABILITY TO DRESS UNAIDED	-.01	.07
INABILITY TO WASH UNAIDED	-.24	.19
INABILITY TO COMMUNICATE	.17	.24
DAYTIME WANDERING	.06	-.33
INABILITY TO MANAGE STAIRS	.22	-.50
INABILITY TO FEED	-.73	.20
IMPAIRED VISION	.08	-.09
IMPAIRED HEARING	-.04	.12
UNCOOPERATIVE BEHAVIOUR	.12	.12

* Significant at the .05 level

When the behaviour patterns of the caregiver are correlated with enjoyment, an inverse relationship is noted between frequency of occurrence of unreasonable/frequent demands, sleeping disturbances and enjoyment; that is, the

less frequent the demands and the sleeping disturbances, the more enjoyment is experienced.

TABLE 27 Behaviour Patterns of Care Recipient with Satisfaction

BEHAVIOUR PATTERN	FREQUENCY	LEVEL OF DIFFICULTY
SLEEPING DISTURBANCES	-.12	-.16
INCONTINENCE	.20	.29
FALLING	.07	.00
INABILITY TO GET IN/OUT OF BED	.12	.04
INABILITY TO GET ON/OFF COMMODE	.23	-.02
DANGEROUS IRRESPONSIBLE BEHAVIOUR	-.06	.30
INABILITY TO WALK UNAIDED	.11	-.14
UNREASONABLE/FREQUENT DEMANDS	-.38*	.49
PHYSICALLY AGGRESSIVE BEHAVIOUR	-.46*	-.76
INABILITY TO DRESS UNAIDED	-.01	-.09
INABILITY TO WASH UNAIDED	.20	.04
INABILITY TO COMMUNICATE	-.35*	-.43*
DAYTIME WANDERING	-.12	.47
INABILITY TO CLIMB STAIRS	-.16	-.50
INABILITY TO FEED	.14	-.49
IMPAIRED VISION	-.21	.28
IMPAIRED HEARING	-.05	-.13
UNCOOPERATIVE BEHAVIOUR	-.53*	-.36

* Significant at the .05 level

Inverse relationships are also noted for frequency of occurrence of unreasonable/frequent demands, physically aggressive behaviour, inability to communicate, uncooperative behaviour and satisfaction; that is, the higher the frequency of occurrence of these behaviour patterns, the less satisfaction is experienced. In addition, an inverse relationship also exists between level of difficulty of communication problems and satisfaction; that is, the higher the level of difficulty experienced with communication, the less satisfaction is experienced.

TABLE 28 Lifestyle of Caregiver with Enjoyment and Satisfaction

VARIABLES	ENJOYMENT	SATISFACTION
INTRUSION ON PRIVACY	.24	.25
INABILITY TO LEAVE UNSUPERVISED	.08	-.01
INTERFERENCE WITH CAREER	.05	-.21
RELUCTANCE TO BE CARED FOR BY ANOTHER	.02	-.16
RESTRICTION IN HOME ENTERTAINMENT	-.38*	-.30*
INABILITY TO TAKE VACATION	.10	-.09
INABILITY TO SOCIALIZE OUTSIDE HOME	.04	-.07
INABILITY TO PURSUE A HOBBY	.07	-.11
INTRUSION ON CHILDREN'S LIVES	-.05	-.09
FINANCIAL HARDSHIP	.20	-.22
PHYSICAL LIMITATIONS OF HOME	.06	-.08
INABILITY TO SLEEP SOUNDLY	.32	-.15
OTHER	-.24	.37

* Significant at the .05 level

There is an inverse relationship between satisfaction, enjoyment and restriction in entertaining at home; that is, the more the restriction, the less satisfaction and the less enjoyment in caregiving is experienced.

TABLE 29 Emotional Impact with Enjoyment and Satisfaction

VARIABLE	ENJOYMENT		SATISFACTION	
	FREQUENCY	LEVEL	FREQUENCY	LEVEL
FRUSTRATION	-.10	-.36*	-.11	-.30
ANXIETY	-.18	-.04	.38	-
CHANGE IN FEELINGS	-.02	-	-.12	-
CONSIDERED NURSING HOME	.13	-	-.30*	-
WILL CONSIDER NURSING HOME	.21	-	-.07	-
AGGRAVATION	-.02	-.50*	-.12	-.03
RESENTMENT	.06	.06	-.16	-.27
SATISFACTION	-.07	.21	-	.48*
ENJOYMENT	-	.68*	-	-.16

* Significant at the .05 level

Inverse relationships are indicated between the level of difficulty of frustration and aggravation with enjoyment; the lower the difficulty experienced, the more the enjoyment. There is also an inverse relationship between the frequent experiencing of satisfaction and consideration of nursing home placement.

TABLE 30 Family Relationships and Support with Enjoyment and Satisfaction

VARIABLE	ENJOYMENT	SATISFACTION
RELATIONSHIP WITH SPOUSE	-.25	-
RELATIONSHIP WITH CHILDREN	.28	.01
RELATIONSHIP WITH FAMILY MEMBERS	.26	-.20
SPOUSAL AID	.60*	-
FAMILY AID	-.16	.17
CHILDREN'S AID	-.22	.40
FREQUENCY OF FAMILY VISITS	.22	.04
HELPFULNESS OF FAMILY VISITS	.26	.12

* Significant at the .05 level

There is a positive correlation between those who receive help from their spouse and enjoyment.

TABLE 31 Formal Services with Enjoyment and Satisfaction

SERVICE	ENJOYMENT	SATISFACTION
INSTITUTIONAL RESPITE	.31*	-.19
SHORT TERM RESPITE	-.10	.00
MEALS ON WHEELS	.00	-.27
HOUSEWORK	-.17	.14
PERSONAL CARE	.15	.23
DAY CARE	.24	.19
VISITING NURSE	-.37*	-.52*
PHYSIOTHERAPY	.24	.37

* Significant at the .05 level

There is a positive correlation between enjoyment and institutional respite indicating that those who use the services experience more enjoyment in the role. An inverse relationship exists between nursing services and satisfaction.

TABLE 32 Hours of Services with Enjoyment and Satisfaction

VARIABLE	ENJOYMENT	SATISFACTION
NUMBER OF HOURS OF FORMAL SERVICES RECEIVED	.09	.08
NUMBER OF EXTRA HOURS WOULD FIND BENEFICIAL	-.35*	-.34
WILLINGNESS TO PAY FOR ADDITIONAL HOURS OF SERVICE	-.15	-.05

* Significant at the .05 level

There is an inverse relationship between enjoyment and the perceived need for additional hours of formal services.

CHAPTER 4

DISCUSSION OF THE RESULTS

I. INTRODUCTION

This study addresses itself to the issue of care providers' needs and concerns. By concentrating on a very specific population, it was hoped that certain definite characteristics of care would be brought to light that would aid professionals in the assessment of service delivery. The information provided by the respondents in this study has suggested some answers to the research questions while at the same time raising new questions.

II. PROFILE OF THE CAREGIVER AND THE ELDERLY

The results of this study have revealed a profile of a caregiver who is female, either married (52%) or single (48%), aged 59 years or more; she is caring for either a parent or spouse and does not have any serious health problems. She lives in a household with the care recipient and one other person. She has lived with her elderly relative for over twenty years and has provided full time care for an average of five years. She has some high school education and her income on the average is $10,000 or less per annum. She receives an average of four hours of assistance from formal services per week.

She does not find the caregiving role to be an enjoyable one; she is very likely to experience a high level

of frustration, aggravation and anxiety almost daily. She is unable to take a vacation, socialize outside the home, entertain at home or sleep soundly at night. She has very little privacy. However, she does take satisfaction in her role as caregiver.

A profile of the elderly relative being cared for at home, in general, reveals a spouse or parent who is at least 80 years of age (72%) and who has one or more living children (50%). Over 50% of the care recipients are diagnosed as having Alzheimer's Disease or Senile Dementia.

It is clear that the caregiving role includes a variety of negative factors that contribute to making the experience a difficult one. Research has shown that normally the presence of these factors would lead to high stress and ultimately institutionalization. The comparison between these studies and this one reveals some noteworthy points.

The subjects of this study are similar in characteristics to others in that the caregiver is generally female and approaching old age as well (Robinson & Brody, 1966). The majority of the elderly being cared for at home have children who make this possible. Soldo and Myers (1976), have confirmed that those who are low fertility women or childless are at high risk of institutionalization.

However, there are some noteworthy points of

similarity and difference; Statistics Canada (1986), reports that the mean age of caregivers of elderly parents is 53, while the mean age in this study is 59. This is a fairly elderly group of caregivers providing high level care.

Kooperman-Bryden (1979), found that the primary family caregiver invested over 28 hours per week in physical and psychological assistance; whereas the subjects in this study are involved in care on a 24 hour per day basis with only 4 hours per week of assistance from formal services.

Snyder & Keefe (1985), found that 70% of caregivers report that their health was negatively affected by caregiving responsibilities while the caregivers in this study do not report significant health problems. In addition, Snyder & Keefe (1985), reported that the longer that individuals are involved in caregiving, the more likely they will report health problems. However the respondents in this study have been living with the care recipient for an average of 30 years or more and providing high level care on the average of 5 years or more. The individuals described in this study do not demonstrate unusual resources or characteristics that would help explain their wherewithal to function as high level caregivers. Rather the contrary is true. There is however, one factor that may contribute to their coping ability. Of the respondents, 62.1% live with at least one. other person in the household

other than the care recipient. This may be significant in terms of aiding the caregiver in continuing in that role for an extended period of time. This interpretation is supported by Calfound et al (1979), who found in a study of three-generational homes that 60% of respondents reported no adverse affects of caregiving in spite of the fact that these families provided up to 40 hours per week of direct personal care.

The caregivers in this study can be described as being a high risk group in terms of stress. Only one factor, the presence of another family member in the household, appears to contribute to their ability to continue in this difficult role.

III. ANSWERS TO THE RESEARCH QUESTIONS

A. Question 1

What are the most difficult problems encountered by the caregivers providing 24 hour care to an elderly relative?

The results of this study show that sleeping disturbances (51.7%), inability to communicate (55.2%), and the inability to wash unaided (89.7%) are the three most frequent problems encountered on a daily basis by caregiver. In terms of level of difficulty, 64.7% of the respondents found sleeping disturbances and 58.8% found the inability to communicate to be the most difficult to handle.

The absence of other more demanding behaviour

patterns may explain why this population can continue to provide high level care. Given the predominant diagnosis of Alzheimer's Disease and Senile Dementia, it could be expected that the behaviour patterns of incontinence, dangerous/irresponsible behaviour, unreasonable/frequent demands, aggressive behaviour and wandering or uncooperative behaviour would occur as part of the medical problem. Can it be assumed that if these patterns subsequently began to appear that institutionalization would become a reality? If 24 hour care includes relatively simple tasks that have evolved over time and are therefore manageable, perhaps institutionalization does not become an issue until more complex and difficult behaviour patterns emerge.

This hypothesis is supported by Zarit (1980), who found that the instrumental activities of those with Senile Dementia required the most attention and that the burden of care perceived by the caregiver was much less than expected.

In this study it is not the increase of level of care or the frequency of task performance that appear to be high stress factors or predictors of institutionalization. For this group, the caregivers can manage the expectations of care as it presently exists. However, what would be the outcome if the behaviour patterns changed and became more complex? It is important for professionals to become aware of these potential complexities in order to determine the level of service that would be required. Caregivers also

need to be educated about potential changes in care over time so that they can plan accordingly. This is an important role for service deliverers.

The fact that the caregivers and the care recipients have lived together on the average of 20 years or more suggests that the changes in care have occurred gradually over time. These caregivers seemingly have adapted to these changes and the increased demands. Perhaps it is this gradual adjustment that has made their role easier to assume. Is it more difficult to take on high level care as the result of an emergency situation eg: a widowed mother who suffers a stroke and moves in with one of her children and family? Is a sudden change in lifestyle more difficult and stress provoking than the gradual onset of increased care? Are decisions regarding institutionalization more readily made by family members who are suddenly required to provide 24 hour care than for those whose lifestyle has gradually changed over time?

A comparative study of these types of situations may reveal factors that are important for service deliverers to consider in assessing needs and making appropriate decisions. Under what circumstances are institutionalization decisions being made? A high level of home service may be necessary in emergency situations and gradually reduced as the family learns to adjust to the change in lifestyle.

B. Question 2

What are the factors that make continued home management possible?

There are three factors that the majority of the respondents reported that made it possible for them to continue providing care: commitment (79%), family support (76%), home care services (83%). To simplify reporting, the issue of "commitment" and "home care services" will be discussed later in this chapter.

The data offers conflicting information with regards to "Family Support". The respondents, report ongoing family visits (66%). However, of these, only 38% found the visits helpful, 36% did not and 28% did not answer. Frequency of visits is reported by 58% as occurring on a daily to weekly basis. Therefore why are these visits not considered to be more helpful by a larger proportion of the group? At the same time, 73% reported that they did not receive any assistance from other family members. There was some reluctance on the part of the respondents to discuss why such help was not forthcoming. Some have indicated that they did not ask for assistance or stated that family members are "too busy". Given the high frequency of visits, why does the caregiver not perceive him/herself as receiving meaningful assistance from family members? And, if meaningful assistance is not forthcoming, why do 76% of the respondents state that family support is an important factor

in their role?

It may be that a "visit" is not considered useful in either lightening the burden of care or providing a social contact for the caregiver who is confined and immersed in care. There is a reluctance on the part of the caregivers to discuss the whole issue of family support which indicates that this is a sensitive area for discussion. Perhaps the difficulty lies in a feeling of resentment towards family members who are not considered to be "doing their share" and a feeling of disloyalty may arise by discussing these issues with an "outsider" ie-the researcher.

Previous research has also produced similar conflicting information. Zarit (1980), reported that frequency of family visits had a significant effect on the degree of the caregiver's feelings of burden. Apparently the burden is lessened in those situations where more visits were made from other family members to the impaired older person. And yet, Snyder & Keefe (1985), found that of the 43% of caregivers who report receiving help from outside members, only 28% indicated that family help was consistent and regular. These caregivers viewed such relief as insufficient.

Clearly, the dynamics of family relationships and their impact on the caregiver are important for future study, particularly as the focus for elderly care policy is to provide supports that promote care at home.

C. Question 3

How essential is the presence of formal services to the caregiver in maintaining the elderly at home?

The data clearly indicates that formal service delivery is essential to this group of caregivers. Personal care is the most used service for 86% of the respondents. As 90% of this group reported requiring assistance with daily washing of the elderly care recipient, this problem has been alleviated through formal services. Of those using the personal care service, 96% scored 5 on a scale of 1 to 5 for essentiality.

Short term respite was provided to 45% of the group with institutional respite being provided to only 28%. Respondents rated these and other services as highly essential as well. Apparently any formal assistance is deemed necessary as well as useful.

Seventy percent of the group are at present in receipt of 4 to 5 hours per week of formal services and 48% of the group were satisfied with this amount of time. However, 72% indicated a willingness to pay for additional services. There appears to be a discrepancy between these two figures. Perhaps, this particular group who, has been involved in care for quite some time before receiving any formal assistance, are appreciative of the help they are receiving and would not wish to appear ungrateful by stating that the hours of service are insufficient. It is not an

unlikely concept that additional aid would be regarded as useful given the high level of care that is required. However, why they have not sought additional services from a private agency on a fee-for-service basis is not clear, unless one considers that their present income is rather low (less than $10,000.00 per annum).

For this particular group, formal services have eased the burden of care and is cited as one of three factors that make it possible to continue providing it.

D. Question 4

What aspects of daily living are most affected by the role of caregiver?

The respondents reported that the following 5 limitations imposed by caregiving negatively impact on their lifestyle:

a) Inability to leave unsupervised (93.1%);

b) Inability to socialize outside the home (86.2%);

c) Inability to take a vacation (79.3%);

d) Inability to sleep soundly (62.1%); and,

e) Intrusion on privacy (51.7%).

Other studies on stress and caregiving affirm that confinement is the biggest burden (Snyder & Keefe, 1985).

It is not surprising that, given the high level of care being provided, the respondents find these five areas to be burdensome. However solutions are available and have not been utilized. Institutional respite and short term

respite would allow caregivers free time during the week and the freedom to take a vacation. And yet, this population primarily chose personal care services.

It would appear that the daily washing of the care recipient is more difficult to cope with than confinement. Or have the caregivers been involved in this situation for so long that change in the routine is more difficult than the routine itself? Have they lost touch with the social activities available because of the caregiving role? Why have family members not been utilized to allow a social life outside the home for a vacation? Again, this raises the issue of family dynamics and the subsequent impact on the caregiver.

Certainly there are financial restrictions due to a low income which would inhibit certain options, such as "getting away". Vacation "at home" is only possible if the elderly were removed from the home, an option few are willing to take as demonstrated by this group where only 28% made use of "institutional respite". Perhaps the trauma for the elderly associated with a change in his/her environment creates more problems than it would solve. Or perhaps the caregiver, who has chosen not to put their elderly in an institution, would feel guilty about doing so even for a short period of time.

In service delivery policy planning, it is important to consider the caregiver's willingness and "ability" to

utilize and take advantage of services. Counselling and encouragement from professionals may be required so that caregivers can give thought to new options not previously considered. This may help to prevent and alleviate caregiver burnout. Change is not easily accepted, especially when a "workable routine" has been established. If a new option is made possible, it may open access to a new lifestyle that had been previously thought impossible. If consideration is not given to the difficulty that caregivers may encounter in changing their routine, a valid idea for service delivery may fail.

E. Question 5

Is there a relationship between the levels of satisfaction perceived by the caregiver and the caregiving role?

The statistical analysis of variable 115 (those who answered Yes/Satisfaction, No/Enjoyment) does not produce any firm correlations or significant results.

Of the respondents, 93% stated that they derived a sense of satisfaction in providing care, even though there are many negative aspects in their role as care providers as has been previously discussed. Their own personal comments indicate that this feeling of satisfaction in their role of caregiver is related to their own sense of responsibility. A general overview of these comments is provided as follows:

a) "I won't have to answer for anything when he

(father) goes. I wouldn't want to see him anywhere else."

b) "I'm at peace because I know my mother is getting the best of care. Institutional care is not what it's meant to be and people in nursing homes do not get the care that they are supposed to."

c) "If I hadn't cared for her (wife) she wouldn't be alive. It's her right to be in her own home. It's her right and I'm trying to give it to her.

d) "God will reward me for what I am doing (for my parent). I've heard what they do to people in the home."

e) "It's my responsibility to him (father). He wouldn't do well in a nursing home."

f) "It's my duty."

g) "I love my husband deeply. He looked after me when I had back problems."

h) "I'm the only one to care for her (mother) and I'm afraid to put her in the home."

i) "It's my responsibility as a Christian."

j) "The rest of the family want her in the home. I'm able to do for her and I don't want her in the home."

k) "It's my father and I feel responsible towards him. It's not my duty but I feel commitment. My mother wouldn't want a stranger."

This feeling of responsibility towards the elderly experienced by the family caregiver appears to contribute to a sense of satisfaction in that living up to one's own perceived responsibilities enhances one's self esteem. Is this sense of responsibility related to the direct familial relationship between caregiver and care recipient? In the study, 86% of the respondents are caring for either a parent or a spouse. Would the same sense of responsibility and, therefore, satisfaction exist toward a person more distantly related?

While a sense of responsibility is clearly indicated by the respondents' comments, commitment is also a primary consideration. To be involved in a confining, burdensome, unenjoyable role 24 hours a day, and find satisfaction in that role reveals a high level of commitment. This commitment would seem to be the single most important factor that makes care at home possible.

In discussing such issues, the terms "responsibility", "satisfaction", and "commitment" are difficult to operationalize. Examining the open-ended responses of the caregivers reveals far more than the statistical analysis of the variables. Such analysis did not reveal the sense of responsibility that the caregivers so obviously feel. In researching such concepts, it may not always be possible to subject them to the microscope of data analysis. What people say and feel about their experiences

can often be more meaningful and revealing than statistical analysis alone.

F. Question 8

Is there a relationship between the level of enjoyment perceived by the caregiver and the level of care required by the recipient?

While 93% have expressed a sense of satisfaction in the caregiver role, 62% have stated that it is not an enjoyable experience. It has previously been noted that the inability to socialize outside the home, take a vacation, sleep soundly at night, leave the elderly unsupervised and the intrusion on privacy all impact negatively on the caregivers' lifestyle.

In addition, 86% of the caregivers have also expressed a high level of frequent frustration. Some of this frustration is caused by the tasks involved in caregiving. However, other aspects of care contribute to the caregivers' frustration level as expressed by their comments:

a) "Lack of freedom, lack of sleep...it's a hard life."

b) "She doesn't take her medication or eat. I'm not getting my rest. The change in my lifestyle...I don't see the results of my labour."

c) "I can't get out."

d) "...doing the same thing week in and week out and seeing no accomplishment. My father is unappreciative and uncooperative."

e) "Being housebound...I can't get out. She always wants to go home."

f) "You have to watch for she may wander off."

g) "Nothing is normal."

h) "My father is very authoritative and he finds it hard to give that attitude up. He's very nosey and interfering. He tries to maintain control."

i) "Her forgetfulness, she won't listen to me. She thinks I'm nosey. She constantly forgets."

k) "I've always been responsible for myself... looking after my mother now is a heavy burden, mainly because of lack of freedom."

l) "I can't do anything that makes the situation less hectic."

Confinement, lack of freedom and lack of appreciation are all sources of frustration for the caregiver and have a definite impact on the degree of enjoyment that is experienced in their role.

In addition, 66% experience feelings of anxiety and distress. This is primarily caused by worry regarding their own future and therefore the future care of the elderly as indicated by their comments:

a) "...When her behaviour becomes bizarre. I don't understand the new behaviour."

b) "I'm worried about how I'm going to manage financially when she's gone. I have little income."

c) "I gave up my job and I worry about my future and I worry about who will look after my father if I should get sick."

d) "I'm afraid she may have a stroke and I worry about my being able to cope."

e) "He's not the same father that I knew. I never know from one day to the next. His condition reaches a crisis very often."

f) "When she falls or needs medical care."

g) "Watching my mother deteriorate over a prolonged period of time."

h. "Worried that she might die and I could have done something to save her."

It can be gleaned from these comments that the caregivers live in a constant shadow of uncertainty regarding the future: both their own as well as that of the elderly. The elderly relative is not improving and is not likely to improve despite the caregiver's best efforts because of the aging process. With the care of an infant or a convalescing patient there is an expectation that time and effort will result in improvement. The caregiver of the

aged has no such expectation. The daily routine can be expected to increase in intensity and will only cease with the death or the institutionalization of the loved one. Added to this implicit knowledge is the fact that the caregiver also is aging with the inherent risk of potential ill health and reduced energy. Who then will look after the care recipient? Who will care for the caregiver?

While it is apparent that this group of caregivers is committed to their task and derive a sense of satisfaction in "doing the right thing", there are many factors that make the experience one which is riddled with anxiety and frustration and therefore an unenjoyable one.

Changes in the relationship with the elderly person also can have a significant impact on the caregiving role. 83% of the respondents have also experienced a change in feelings towards their elderly relatives. The majority feel pity and sadness about the subsequent change in their relative. Their feelings are not necessarily negative in nature and some have developed closer relationships as indicated by the following comments:

a) "I feel anger. She constantly complains about me. She says that she's left alone even when she's not. I tolerate her but I do not love her."

b) "I feel pity and sadness, but I also feel closer to him than I did before."

c) "I have more demands and it causes me to feel more stress. The staff in nursing homes get shift changes - no one relieves me."

d) Her plight has made me feel more affectionate. While I feel pity, I also have more understanding. I see her greatness and I appreciate her more and more. I see how patient she is with suffering."

e) "Improved. Changed for the better...more loving and caring."

f) "Pity, I can't accept the fact that he's getting old. I'm used to depending on him."

g) "He's more dependent and I'm more responsible than I used to be. He finds it hard to show affection."

i) "I'll feel better when she has another stroke and dies."

The degree of compassion that is felt by some caregivers may enhance their sense of satisfaction while at the same time take away from their enjoyment in the caregiver role. These caregivers watch their loved ones deteriorate, both physically and mentally, on a daily basis. For some, this elicits pity, and for others more negative feelings are experienced. These reactions may be based in part on the previous relationship that existed between the caregiver and the care recipient. While 76% have stated

that they do not feel any resentment towards the elderly relative, it may be that the caregiver did not feel comfortable in expressing feelings of resentment to the researcher.

This population has expressed a high degree of frustration (86%), aggravation (83%) and anxiety (66%). They find the burden of care to be confining; they have few financial resources to call upon to relieve their burden; they receive little support from other family members and they also receive less than one half hour daily of formal services. It would appear that the caregivers' role requires great sacrifice and provides little enjoyment in every day life. The continuing ability to cope daily appears to be related to their own sense of responsibility and commitment. These inner convictions seem to play a large role in their coping ability.

IV COMPARISON BETWEEN SUB-GROUP 115 AND TOTAL POPULATION (STATISTICAL AND CORRELATIONAL ANALYSIS)

The statistical analysis of variable 115 does not produce significant results or firm answers to explain the seeming discrepancy of those who said that caregiving is a satisfying experience (93%) but not an enjoyable one (62%). However there are certain differences that warrant observation.

In the sub-group there are notably higher ratios of care recipients that present certain problems on a daily basis:

Problem	Sub-group (N=17)	Total Population (N=29)
Inability to take vacation	87.3% (N=14)	79.3% (N=23)
Inability to Communicate	64.7% (N=11)	51.7% (N=15)
Intrusion on Privacy	64.7% (N=11)	51.7% (N=15)
Impaired Vision	47.4% (N=8)	41.4% (N=12)
Uncooperative Behaviour	29.4% (N=5)	24.1% (N=7)
Unreasonable/ Frequent Demands	23.5% (N=4)	17.2% (N=5)
Aggressive Behaviour	11.8% (N=2)	6.9% (N=2)

It is clear that both the total population and the sub-group find the inability to take a vacation, intrusion on privacy and communication problems to be difficult with the sub-group showing higher percentages of difficulty. The sub-group also has a higher percentage of those who experience anxiety than the total group (76.5% vs 65.5%). It should also be noted that the respondents in the Sub-group have been involved in full time care for 8 years on the average compared to 5 years for the total group.

While this data analysis does explain why little enjoyment is experienced, it does not provide firm conclusions or insight into why there is such a high degree of satisfaction other than that which has been previously discussed in this chapter. More specific conclusions could possibly be drawn by a statistical analysis and correlational testing of those respondents who answered

YES/ENJOYMENT, YES/SATISFACTION with those who answered NO/ENJOYMENT, NO/SATISFACTION and those who answered NO/ENJOYMENT, YES/SATISFACTION. However, considering the small sample size it would be difficult to make generalized statements. It would be worthwhile for future research to delve further into this aspect of caregiving.

V. CORRELATIONAL ANALYSIS OF ENJOYMENT AND SATISFACTION WITH OTHER VARIABLES

The correlational analysis does not provide firm, significant results. Tentative conclusions can be drawn, with caution, regarding factors that contribute to or diminish satisfaction and enjoyment.

A. ENJOYMENT

The analysis indicates certain factors such as sleeping disturbances, unreasonable/frequent demands, restrictions in entertainment at home, frustration and aggravation take away from the possible enjoyment that a caregiver who is involved in high level care could experience. In addition there is a correlation between those who receive help from their spouse and enjoyment and those who use institutional respite services and enjoyment. However these correlations should be examined in perspective. While sleeping disturbances are a daily problem for 51.7% of the group (N=17), only 11 of the 29 respondents found these to be difficult. Unreasonable/frequent demands are reported by only 7 of the total population. Fourteen of the respondents stated that

there was a restriction in home entertainment but only 9 of the total population found this to be difficult. Therefore, because of the low numbers it would be difficult to state that there is a significant relationship between the above mentioned factors and the experiencing of enjoyment.

Nine of the caregivers have spouses that are not care recipients. Of those, 7 receive help from their spouse. It would be fairly safe to make the statement that there is a positive relationship between those who are in receipt of spousal aid and enjoyment. However, before a clear statement of correlation can be made one should compare those respondents who said NO/ENJOYMENT with those who said YES/ENJOYMENT to determine the significance of spousal aid with enjoyment.

Institutional respite is used by only 8 respondents of the total population. One could make the assumption that there is more enjoyment experienced when the caregiver is able to take a break from the burden of the caregiving role. Again, a clearer indication would be forthcoming by examining those who receive institutional respite and their responses to the enjoyment question. How many of those in receipt of institutional respite stated that they enjoyed the caregiver role?

There would appear to be a significant relationship between aggravation, frustration and lack of enjoyment as over 80% of the respondents report experiencing these

feelings

Perhaps the concept that enjoyment is possible in the performance of care at such high levels is not a realistic one. It would not be surprising that, considering the negative aspects of the caregiver's role, she/he would not enjoy the role. The fact that these caregivers expend great time and effort on behalf of the care recipient appears to be primarily tied more to their sense of commitment than to the fact that the role in and of itself is enjoyable. Service delivery policy should perhaps focus on factors that alleviate the burden and stress of the caregiver role rather than enhancing enjoyment. There is likely to be more congruency among caregivers regarding stress factors and the means that would alleviate stress than what makes caregiving enjoyable. High levels of formal services could be implemented at home and the caregiver may still not enjoy the role but is in a better position to continue to provide care.

B. SATISFACTION

The correlational analysis also does not provide clear cut relationships between satisfaction and other variables. It does not reveal factors that enhance satisfaction. Rather it indicates possible factors that take away from satisfaction such as unreasonable/frequent demands, physically aggressive behaviour, inability to communicate and uncooperative behaviour. Again these

correlations should be examined in perspective.

Unreasonable/frequent demands are reported as occurring daily by only 7 respondents; physically aggressive behaviour is reported by only 5 respondents; uncooperative behaviour is reported by 10 respondents. In addition physically aggressive behaviour is reported to be difficult by only 2 of the 5 respondents with uncooperative behaviour reported by 4 of the 10 respondents as being difficult. As these numbers are rather low, a firm statement of correlation is difficult to make.

Seventeen respondents report inability to communicate as occurring daily with 10 reporting high difficulty. It could be said that communication problems are likely to take away from the caregiver's sense of satisfaction. However considering that 93% of the respondents stated that the caregiving role is satisfying, a correlation between satisfaction and communication problems cannot be shown.

Satisfaction appears to be connected to those variables not subjected to statistical analysis such as loyalty, self esteem and a sense of responsibility as the respondents themselves indicated in their open-ended responses which was previously discussed in this chapter.

CHAPTER 5

CONCLUSION

I. LIMITATIONS

This study focuses on a specific population group and a small sample. Thus, the possibility of generalizing the findings to a larger population is limited.

There was difficulty in operationalizing and identifying the dimensions of certain key concepts, e.g. enjoyment, satisfaction, anxiety, frustration and resentment. This allowed for individual respondent interpretation and may have contributed to inconsistency in responses.

Respondents were also asked open-ended questions. Their responses may be subject to the inherent hazards of ambiguity based on what the respondent was feeling at the time. The respondents may have experienced some tension in answering questions that were very personal in nature to a relative stranger. Therefore, they may not have felt comfortable in answering such questions with complete honesty. The evident superficiality of the dynamics of the relationship established between the interviewer and the respondent in a two hour time span may also have affected the responses.

It is important therefore that future research consider ways to elicit more specific data.

II. RECOMMENDATIONS

While this study is limited in scope and focus, the findings do offer suggestions for policy planning of service delivery to the caregiver. The respondents have shown that while their personal commitment to care is a crucial factor, there are certain aspects of their burden that can be alleviated by formal services.

On the basis of these responses the following recommendations are suggested:

A. Sleeping disturbances are a commonly reported problem that can ultimately affect the mental health and physical well being of the caregiver. If an elderly relative is constantly disturbing the household at night, the caregiver is unlikely to be able to rest. Home care professionals concerned about preserving the coping ability of the caregiver ought to consider unique ways to alleviate this problem. One suggestion is to provide services that allow the caregiver sleeping time during the day. This is more cost effective than the provision of a homemaker at night. Home care professionals should seek ways to elicit the cooperation of other family members. The use of family members in conjunction with formal services could provide such rest time during the day for the caregiver. This cooperative effort also provides a means to incorporate the family in care provision in a productive manner for all involved parties.

B. The dynamics of family relationships is a subject that requires more study. Future research should examine the relationships between a) the caregiver and the elderly, b) the caregiver and other family members and c) the elderly and other family members. An understanding of these relationships is important in the assessment and implementation of formal services. The involvement of the extended family in the care of the elderly may enhance the coping ability of the caregiver and relieve the burden of care. Home care professionals can use their skills to develop the resources of the whole family. The use of family counselling coupled with individual counselling is one means of handling unresolved issues between and among family members, thereby enhancing this valuable resource. Incorporating the family in home care removes the sense of isolation and confinement that caregivers experience. The responsibility is one that becomes shared by all family members. Formal services then becomes a tool used by the whole family rather than a primary resource.

C. Professionals should also seek to establish a network system between and among caregivers. Opportunities to socialize and communicate with others experiencing similar concerns can alleviate anxiety. For those who have total responsibility for an elderly relative, isolation can increase fear and diminish feelings of self-esteem thereby increasing stress levels.

Personal contacts established in a group setting can continue to be maintained by use of the telephone providing the caregiver with a social contact and mutual support. However the initial establishment of a caregiver support group will involve some commitment by formal services to provide homemakers which will allow the caregivers the opportunity to participate.

D. The training of homemakers should include information sessions on the emotional impact of the caregiver's role. Homemakers should be aware of the emotional implications on the lifestyle of the caregiver. They can be trained to identify crisis trigger points. The homemaker as the "front line" worker is in the best position to note increasing stress levels and notify appropriately trained professionals so that issues can be addressed and decisions can be made prior to the arising of an emergency situation that could result in premature decisions regarding institutionalization.

E. The tools of assessment used by formal services to determine appropriate levels of service should incorporate categories of care that will highlight potential stress areas. Assessment forms should examine such factors as the following:

1. Degree of family support
    a) amount of help received
    b) number and frequency of family visits

c) caregiver's attitude towards family and their existing support

d) identification of a supportive family member

2. Emotional responses of the caregiver

a) aspects of care that cause high frustration, aggravation, anxiety and resentment

b) caregiver's own ability to alleviate stress

c) existing relationship dynamics between caregiver and care recipient

d) caregiver's ability to accept change

3. Time involved in active physical care

4. Potential existing resources that can be implemented in cooporation with formal services

Categories of care can thus be established to identify not only high stress areas but also those situations that indicate potential problems.

F. High level formal services should be available for those caregivers who take on the role as the result of an emergency situation. This would avoid inappropriate and/or premature decisions of institutionalization. These services can then be reduced over time allowing the family to adjust to the dramatic changes invoked by the emergency.

This study has identified that commitment, family support and formal services are key factors for this population of caregivers. Future efforts should focus on enhancing these factors to ensure that the caregiver is given the best opportunity to continue with the important task that they have undertaken, thereby ensuring appropriate care of the elderly at home. This can best be achieved by involving the caregivers in the development of services as well as expanding service delivery to include unique approaches to meet the needs of all concerned.

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APPENDIX I

General Information Letter

Dear Sir or Madam:

I wish to follow-up on a recent conversation between yourself and a staff member of the St. John's Home Care Program. You were then invited to participate in a research project that I am conducting as part of the requirements for a Master's Degree in Social Work.

This research is concerned with the problems that families experience in providing care for their elderly relatives. Hopefully, the results of this research will help health professionals, health educators, social workers, and others among the service professionals to better understand some of the important factors affecting the provision of care to the elderly by family members (caregivers) and to become more effective in their attempts to provide needed services.

Your participation in this study will involve my visiting you at your home to ask you a series of questions on this subject. My visit will last about 1 to 1-1/2 hours. Your collaboration in this project will carry no risk to you in any way. Your relationship with St. John's Home Care will not be affected.

You need not be concerned about the service that you are presently receiving being decreased. However, while I will benefit from your participation in this study, you should not expect your present service will increase because of your participation. If you should agree to participate, I will give you a consent form for your signature, which indicates that you understand your role in this study and that you agree to participate. This form is for your protection. In addition, you may withdraw from the study at any time; even after having given your consent.

Measures have been taken to ensure that I, the investigator, will be the only person having access to the identifying material connecting you with the specific set of information which you will be providing and this identifying material will be destroyed by me as soon as the study is completed. The information which you are asked to volunteer will be combined with other information collected from other equally anonymous persons and translated into numerical and statistical findings. In this form, and in this form only, will it become part of a general report.

This general report will be submitted to the School of Social Work, Memorial University of Newfoundland, and the St. John's Home Care Program. If you wish, a copy will be made available to you as well.

I will be contacting you shortly to set up an interview appointment that is mutually convenient. If you have any questions or require further information, please do not hesitate to ask at that time, or you may contact me at the telephone number below.

Sincerely,

Carol Fagan
Master's Candidate
School of Social Work
Memorial University of
Newfoundland
737-3095

APPENDIX II

INFORMED CONSENT FORM FOR RESEARCH SUBJECTS

I, the undersigned, understand that the purpose of this research project is to gain better understanding of the factors involved in the provision of care to elderly persons by family members.

I understand that, in order to safeguard the confidential nature of the information collected from me, an identification number will be used and all the identifying material will be stored in a place accessible only to the investigator, and destroyed when the study is completed. The information collected from me will be used as part of a large accumulation of similar information provided by other equally anonymous individuals, and reported in numerical and statistical form only. It is my understanding that the information I volunteer will not be accessible to the St. John's Home Care Program or anyone other than the researcher.

I understand that there will be no risk to me resulting from my acceptance or refusal to participate in the project. My relationship with the St. John's Home Care Program will not be affected in any way. My consent is totally voluntary and given with the understanding that I my withdraw at any time.

I agree to participate in this research project by completing a questionnaire, which will be used in an interview with the investigator.

DATE _____ SIGNATURE _____

APPENDIX III

QUESTIONNAIRE

IDENTIFICATION NUMBER:_____

SECTION A

The following set of questions asks basic information such as age, sex, income etc. Rather than go through each one with you, I'll ask you to complete it by hand while I go through the questions you've already answered to make sure that I haven't left out anything. If you don't understand the question, please feel free to ask about it.

Q1. Your age _____ years

Q2. Your sex _____Female _____Male

Q3. What is the relationship between you and your elderly relative? (Circle one)

1. Spouse
2. Mother/Father
3. Grandmother/Grandfather
5. Non-relative
6. Cousin
7. Other (Specify)_____

Q4. How many children do you have? _____

Q5. Who else lives here with you and your _____?

1. Spouse
2. Spouse/Children
3. Children
4. Other relatives
5. Non-relative
6. Parents
7. Other (Specify)_____

Q6. Of those children living at home, how many are:

1. 0 - 5 years _____
2. 6 - 12 years _____
3. 13 - 18 years_____
4. 19 + years_____

Q7. How many children (19+ years living away from home live in close proximity to your _____? (St. John's Metro Area)

Q8. Your marital status (Circle one):

1. Married
2. Widowed
3. Single
4. Separated
5. Divorced
6. Other (Specify)_____
7. N/A

Q9. Do you live in (Circle one):

1. Your own home
2. Your elderly relative's home
3. A house/apartment rented by you
4. A house/apartment rented by your elderly relative

Q10. Are you currently (Circle one):

1. Employed full time (away from home)
2. Employed part time (away from home)
3. Unemployed
4. Retired
5. Full time homemaker
6. Other (Specify)_____

Q11. What was your approximate family income from all sources, before taxes, in 1985, excluding your elderly relative? (Circle one)

1. Less than $10,000
2. $10,000 - $14,999
3. $15,000 - $19,999
4. $20,000 - $24,999
5. $25,000 - $29,999
6. $30,000 - $34,999
7. $35,000 - $39,999
8. $40,000 - $44,999
9. $45,000 - $49,999
10. $50,000 or greater

Q12. Medical diagnosis(es), please list all.

_____ _____

_____ _____

Q13. Please indicate the level of schooling your have received. (Circle as many as applicable)

1. Some elementary
2. Some high school
3. High school diploma
4. Some university
5. University degree
6. Some vocational school
7. Vocational/Technical certificate

SECTION B

The next set of questions asks for similar information about your elderly relative.

Q14. Age of elderly relative _____ years.

Q15. Sex of elderly relative. _____Female _____Male

Q16. Marital status of elderly relative. (Circle one)

1. Married
2. Widowed
3. Single
4. Separated
5. Divorced
6. Other (Specify)_____
7. N/A

Q17. Number of living children_____.

Q18. Number of years/months living with you_____/_____.

Q19. Number of years/months - 24 hour care _____/___.

Q20. Does your elderly relative require special equipment or aids at home?

_____Yes _____No

Q21. If you answered "Yes" to Q20, please identify the types of equipment or aids in use.

_____ _____

_____ _____

SECTION C

The next set of questions deal with the different kinds of behaviour patterns that your elderly relative may have. I will list the behaviour pattern and ask you to first identify those that are pertinent to your elderly relative. Then I will ask you to tell me how frequently the behaviour occurs (ie: daily, weekly, monthly) and how difficult this is for you on a scale of one (1) to five (5), with one (1) indicating no difficulty and five (5) indicating great difficulty.

Q22

	Behaviour	Frequency of Occurrence			Level of Difficulty				
1.	Sleep Disturbances	D	M	Y	1	2	3	4	5
	a) Night Wandering	D	M	Y	1	2	3	4	5
	b) Toileting	D	M	Y	1	2	3	4	5
	c) Calling out	D	M	Y	1	2	3	4	5
2.	Incontinence of feces/urine	D	M	Y	1	2	3	4	5
3.	Falling	D	M	Y	1	2	3	4	5
4.	Inability to get in/out of bet unaided	D	M	Y	1	2	3	4	5
5.	Inability to get on/off Commode	D	M	Y	1	2	3	4	5
6.	Dangerous or irresponsible behaviour	D	M	Y	1	2	3	4	5
7.	Inability to walk unaided	D	M	Y	1	2	3	4	5
8.	Inability to walk	D	M	Y	1	2	3	4	5
9.	Unreasonable/frequent demands	D	M	Y	1	2	3	4	5
10.	Physically aggressive behaviour	D	M	Y	1	2	3	4	5
11.	Inability to dress unaided	D	M	Y	1	2	3	4	5

	Behaviour	Frequency of Occurrence			Level of Difficulty				
12.	Inability to wash and/or shave unaided	D	M	Y	1	2	3	4	5
13.	Inability to communicate	D	M	Y	1	2	3	4	5
14.	Daytime wandering	D	M	Y	1	2	3	4	5
15.	Inability to manage stairs alone	D	M	Y	1	2	3	4	5
16.	Inability to feed unaided	D	M	Y	1	2	3	4	5
17.	Impaired vision	D	M	Y	1	2	3	4	5
18.	Impaired hearing	D	M	Y	1	2	3	4	5
19.	Uncooperative behaviour	D	M	Y	1	2	3	4	5

SECTION D

This section asks questions about your daily life and how it is affected by having your _____ live with you. I will list certain conditions that providing care for your _____ may cause and ask you to indicate if your life is affected and to what extent on a scale of 1 to 5, with 1 representing no effect and 5 representing a major effect.

Q23.

	Condition or Situation	No Effect				Major Effect
1.	Intrusion on privacy	1	2	3	4	5
2.	Inability to leave elderly relative unsupervised	1	2	3	4	5
3.	Interference with career	1	2	3	4	5
4.	Interference with desire to pursue a career	1	2	3	4	5
5.	Reluctance of your elderly relative to be cared for by someone else	1	2	3	4	5
6.	Restriction in entertaining in your home	1	2	3	4	5
7.	Inability to take a vacation	1	2	3	4	5
8.	Inability to socialize outside the home	1	2	3	4	5
9.	Inability to pursue a hobby	1	2	3	4	5
10.	Intrusion on children's lives	1	2	3	4	5
11.	Financial hardship	1	2	3	4	5
12.	Physical limitation of the home (eg: stairs)	1	2	3	4	5
13.	Inability to sleep soundly at night	1	2	3	4	5
14.	Others (please specify)	1	2	3	4	5

SECTION E

This set of questions focuses on the services that your are presently receiving, how helpful these services are, and what kinds of service would be more helpful or more appropriate. First, I will ask you to identify those services that you are presently receiving and to indicate how essential these services are in aiding you to maintain your elderly relative at home on a scale of 1 to 5, with 1 representing **Not Essential** and 5 representing **Very Essential**. By helpful, I mean specifically would you be able to keep your relative at home without the present service as it exists. I am not asking about the quality of the service, but rather how essential the service is to you.

Q24.

		Not Essential				**Very Essential**
1.	Institutional respite (eg: for vacation)	1	2	3	4	5
2.	Short term respite (during day or night)	1	2	3	4	5
3.	Meals on Wheels	1	2	3	4	5
4.	Housework	1	2	3	4	5
5.	Personal care	1	2	3	4	5
6.	Day Care	1	2	3	4	5
7.	Day hospital	1	2	3	4	5
8.	Visiting nurse	1	2	3	4	5
9.	Physiotherapy	1	2	3	4	5

SECTION F

The next set of questions will address the kinds of stress that you may experience in caring for your elderly relative. It is well recognized that the care of the elderly can be difficult at times. I have already asked you about the difficulties of the physical aspects of providing care. Now I would like you to identify other factors that you personally find stressful. I will ask you a list of questions based on those areas that are known to be stressful for family caregivers and ask you to indicate if this is the case with you also. I would like you to consider each question carefully and answer as honestly as you feel you are able.

Q25. Could you tell me how you and your _____ came to live together?

Q26. Is living with your _____ an enjoyable experience for you?

yes ____ no ____ 1 2 3 4 5

Q27. Do you feel good about providing care (Does it give you a sense of satisfaction in your life) for your _____?

yes ____ no ____ 1 2 3 4 5

Why or why not? _____

_____

Q28. Do you feel frustrated while caring for your _____?

yes ____ no ____ 1 2 3 4 5

If yes, how often? Daily __ Weekly __ Monthly __

What causes you to feel this way? _____

_____

Q29. Are there times that you feel anxious (worried, distressed) while providing care to your _____?

yes _____ no _____ 1 2 3 4 5

If yes, how often? Daily __ Weekly __ Monthly __

What causes you to feel this way? _____

_____

Q30. Have your feelings changed towards your _____?

yes _____ no _____

Why or why not? _____

_____

Q31. Have you ever considered it necessary to place your _____in a nursing home?

yes _____ no _____

If yes, why? _____

_____

Q32. If not, would you ever consider such a possibility in the future?

yes _____ no _____

Why or why not? _____

_____

Q33. Does your _____ condition ever cause you to feel aggravated (angry, impatient)?

yes _____ no _____

If yes, how often? Daily __ Weekly __ Monthly __

If yes, what makes you angry? _____

_____

Q34. Do you ever resent having to care for your _____?

yes _____ no _____ 1 2 3 4 5

If yes, why? _____

_____

Q35. How has your relationship with your spouse been affected by having your _____ live with you?

Has it:

1. Improved ___ 2. Deteriorated ___

3. Stayed the same ___ 4. N/A ___

If 1 or 2, in what way? _____

Q36. Has your relationship with your children been affected by having your _____ live with you?

Has it:

1. Improved ___ 2. Deteriorated ___

3. Stayed the same ___ 4. N/A ___

If 1 or 2, in what way? _____

_____

Q37. Has your relationship with other family members been affected by having your _____ live with you?

Has it:

1. Improved ___ 2. Deteriorated ___

3. Stayed the same ___ 4. N/A

If 1 or 2, in what way? _____

_____

Q38. Does your spouse help you in the day-to-day care?

yes _____ no _____ N/A _____

If yes, how? If no, is there any particular reason?

_____

_____

Q39. Do your children help you in the day-to-day care?

yes _____ no _____ N/A _____

If yes, how? If no, is there any particular reason?

_____

_____

Q40. Do you receive help from other family members?

yes _____ no _____ N/A _____

If yes, how? If no, is there any particular reason?

_____

_____

Q41. Does your _____ receive visits from other family members?

yes _____ no _____ N/A _____

If yes, how often? Daily __ Weekly __ Monthly __

Q42. Are these visits helpful (beneficial) for you either directly or indirectly?

yes _____ no _____ N/A _____

Why or why not? _____

_____

Q43. What factors enable you to continue to manage the care of your _____?

_____

_____

Q44. Which of the following services are your presently receiving? (Please list all)

Personal Care _____ Short term Respite _____

Visiting Nurse _____ Institutional Respite _____

Housework _____ Day Care _____

Physiotherapy _____ Meals on Wheels _____

Q45. Are there services that I have just mentioned that you were unaware of?

yes _____ no _____

Q46. Which of those services would you find appropriate for your situation?

_____ _____

Q47. Do you have any suggestions for new services that could be implemented that you would find useful? (eg: nightly respite, support groups, counselling).

_____ _____

_____ _____

_____ _____

Q48. How may hours of home care service per week do you receive presently? _____

Q49. How many hours would you find beneficial? _____

Q50. If new or additional services become available would you, the family or your _____ be able to pay for a portion of the cost?

yes _____ no _____